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**Why do individuals comply with mass  
drug administration for lymphatic  
filariasis?**

**A case study from alor district, indonesia**

**2008**

**Submitted by Alison Krentel  
for the degree of PhD**

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---

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## ABSTRACT

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Lymphatic filariasis (LF) is a parasitic disease affecting more than 120 million people; over a billion persons live at risk for infection. Filariasis does not kill, but rather disables; making it an important public health and socio-economic issue facing developing countries. In 1998, the Global Programme to Eliminate LF (GPELF) was created to eliminate LF by 2020 using mass drug administration (MDA) requiring the entire eligible population living in endemic areas to take treatment once a year for 4-6 years.

Challenges to elimination include: (1) convincing asymptomatic persons to comply; (2) maintaining high levels of compliance; (3) managing adverse reactions. Research on compliance has focused on associated factors rather than on influences. GPELF recognises the relevance of this information to its success and has called for increased research on individual motivations.

This study aims to make an original contribution to existing research by describing the reasons people comply with treatment within the context of Alor District. By using theoretical perspectives from social dilemma theory and health promotion theories, the research examines how various elements may influence a person to cooperate and consume LF treatment. Research methods include a preliminary quantitative survey (2004) (n=336) and in depth interviews (2005) (n=43) with compliers and non-compliers in Alor District, Indonesia.

Analysis of results shows non-health related factors are the strongest reported influences on compliance; namely emotions, coercion, power, hierarchy and norms. Lay beliefs about disease reveal complex interpretations which do not necessarily predict compliance. The research demonstrates the complexities of interventions in societies undergoing transition from traditionally-based towards increased development.

Research recommendations include re-evaluating present theoretical reasoning behind GPELF-recommended social mobilisation to include group interaction and cooperation, which have shown to be more appropriate in encouraging compliance. Furthermore, this research recommends wider use and promotion of non-health related benefits to LF treatment.

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## KEY ABBREVIATIONS AND GLOSSARY OF INDONESIAN TERMS

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AIDS	Acquired Immunodeficiency Syndrome
<i>Asing</i>	foreign
<i>Bapak</i>	Sir, Mister, father
<i>BKKBN</i>	<i>Badan Koordinasi Keluarga Berencana Nasional</i> – National Family Planning Organisation
<i>Boa besar</i>	Big fruit (hydrocele)
<i>Boleh</i>	may, to be permitted to
CHW	Community health worker (see <i>kader</i> )
<i>Cinta</i>	to love, love
<i>Cocok</i>	to be suitable or in agreement
DALYs	Disability Adjusted Life Years
<i>Darah</i>	blood; also as in <i>darah kotor</i> – dirty blood; <i>darah manis</i> – sweet blood; <i>darah pahit</i> – bitter blood
DEC	Diethylcarbazine
<i>DepKes</i>	<i>Departemen Kesehatan RI</i> or the National Department of Health
DHA	District Health Authority
<i>Dinas Kesehatan</i>	District Health Authority (in Alor, followed by <i>Kabupaten</i> <i>Alor</i> or district of Alor)
ELF	Elimination of Lymphatic Filariasis
ELKAGA	<i>Eliminasi Kaki Gajah</i> or Elimination Programme for LF in Indonesia
GPELF	Global Programme to Eliminate Lymphatic Filariasis
<i>Gotong royong</i>	Working together for a common goal
GSK	GlaxoSmithKline
GTZ	German Agency for Technical Cooperation



HIV	Human Immunodeficiency Virus
<i>Ibu</i>	Mrs., Madam, mother
IEC	Information, Education and Communication
<i>Ikat</i>	Woven fabric which is part of the traditional heritage of eastern Indonesia, whereby each district (and sometimes sub-district) has a special pattern. Ikats are worn as clothes, used as blankets and to carry babies.
KAPB	Knowledge, Attitudes, Practices and Behaviour Survey
<i>Kader</i>	Community health worker (see CHW)
<i>Kaki gajah</i>	Elephant leg (lymphoedema and/or elephantiasis)
<i>Kepala desa</i>	Head of village / village chief
<i>Komando</i>	Command or order (referring to the Indonesian military)
<i>Kulit</i>	Skin
LF	Lymphatic filariasis
<i>Malu</i>	Shame; embarrassment; root word for <i>kemaluan</i> or genitals
MDA	Mass drug administration
Mf	Microfilaria
<i>Moko</i>	Traditional brass drum used for the bride price in Alor district
NHS	National Health Service (UK)
NIHRD	National Institute for Health and Research Development
<i>Nrima</i>	Passive acceptance
NTD	Neglected Tropical Disease
NTT	Nusa Tenggara Timur (province which includes Alor District)
<i>Posyandu</i>	Health post (at village level – midwife)

<i>Pustu</i>	Primary health care centre (at village level – nurse and midwife)
<i>Puskesmas</i>	Primary health care centre (at sub-district level)
<i>Raja</i>	King
<i>Rame-rame</i>	Busy, many people around
RT	Rukun Tetangga: a neighbourhood association, the lowest administrative unit in a village or city. (amended from Ahli Bahasa dictionary)
RW	Rukun Warga: the administrative unit at the next-to-lowest level in city, consisting of several RTs. (amended from Ahli Bahasa dictionary)
<i>Rugi</i>	To suffer a financial loss or to lose out
<i>Sekretaris desa</i>	The secretary of the village – usually the second in command after the head of the village
SISKES	Stands for <i>Sistem Kesehatan</i> ; the GTZ programme in eastern Indonesia to strengthen the district health authority following decentralisation
<i>Suku sulung</i>	Oldest clan
<i>Tokoh masyarakat</i>	Community leader
<i>Tubuh bersih</i>	Literally means a clean body, but it also means one who has no intentions to use magic or experience in doing so
WHO	World Health Organization

## **A NOTE TO THE READER**

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Throughout this document, I have written Bahasa Indonesia words in italics. Their meanings are either listed in the section on abbreviations and glossary of Indonesian terms or are footnoted. Some terms are used throughout the dissertation in their Indonesian form, as they contain meanings which would be lost in translation.

When using verbatim quotes from respondents, I include the full quotation in Bahasa Indonesia in the footnote for reference. Where I summarise comments from respondents I do not include the full Bahasa Indonesia text. All quotes from respondents, summarised or directly quoted, are italicised.

The inclusion of C or NC before the respondent identification number indicates whether they were self-reported compliers or non-compliers with MDA.

## INTRODUCTION

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Considered a neglected tropical disease (NTD) by the World Health Organization, lymphatic filariasis (LF) has not seen the international attention that other infectious diseases in tropical countries have received through large-scale initiatives like the Global Fund for AIDS, Tuberculosis and Malaria. Within the last decade however, the elimination of LF has become an important priority in international public health. In 1998, the Global Programme for the Elimination of LF (GPELF) was launched combining the efforts of international research institutions, pharmaceutical companies and national health ministries with the specific goal of “the elimination of lymphatic filariasis as a public health problem by 2020” (page 7) (World Health Assembly Resolution 50.29) (WHO 2004). Lymphatic filariasis does not kill; rather it disables individuals, sometimes permanently, and prevents them from living productive lives. LF is endemic in 43 out of 50 countries considered to be least developed (Goldman et al. 2007) and the global disease burden in 2002 was estimated to be 5.549 million DALYs (Molyneux et al. 2003). Elimination of LF would significantly reduce economic loss at both individual and national levels and would provide better conditions for people living in endemic communities helping them to break out of a cycle of poverty (Ramu et al. 1996; Evans et al. 2001; Babu and Nayak 2003b).

The elimination of LF (in areas where loiasis and onchocerciasis are not co-endemic) depends on the participation of endemic communities worldwide in consuming one or two drugs (Diethylcarbamazine and Albendazole) in an annual mass drug administration (MDA) for the duration of 4 to 6 years, regardless of whether they are infected with the parasite (Ottesen 2000). In 2006, GPELF had started treatment programmes covering 400 million people, out of 1.3 billion people living at risk (Goldman et al. 2007). MDA achieves results at both the personal level – by treating those individuals who may be infected with the parasite and at the community level – by providing communities an opportunity to prevent future generations from infection with LF.

Prior to MDA, carriers of the parasite may not know their infection status as only a percentage will develop chronic manifestations of LF like elephantiasis or hydrocele. Furthermore, testing and diagnosis is not a pre-requisite to consumption of the drugs. Those who carry the parasite may suffer adverse reactions, albeit not life threatening, following treatment. These tend to be strongest in the early years of MDA when microfilarial rates remain high.

Commonly cited barriers to the success of the global LF elimination programme are the difficulty of achieving and maintaining a sufficient coverage rate and a declining coverage rate due to initial adverse reactions to the medication (Evans et al. 2001; Sunish et al. 2003).

Most of the current literature investigates factors associated with compliance and non-compliance rather than the reported influences which may impact individual choices to comply with treatment. Furthermore, there is scarce literature on the socio-cultural aspects of lymphatic filariasis. Recent calls have been made for incorporating socio-cultural information into LF elimination campaigns in order to improve compliance (Wynd et al. 2007c). Moreover in 2004, the international LF research community recommended that investigation into factors affecting compliance is an immediate need and listed it as part of their global strategic research plan (Malecela-Lazaro and Twum-Danso 2004). This research responds to these calls by describing, in relation to the Alor people, their understanding of the causes and consequences of lymphatic filariasis and the reasons they themselves express for compliance and non-compliance with treatment; so as to contribute to the formulation of recommendations to the global programme for improvement of MDA effectiveness.

Coverage with the MDA in the district of Alor in eastern Indonesia has been good (>80% as reported by the District Health Authority in Alor) throughout five years of MDA and mf rates have declined as a result. Because of this, greater understanding of the mechanisms at work which promoted compliance throughout the MDA is needed so that the success in Alor might be reproduced in other areas. Furthermore, as the reported rates (>80%) may not reflect the true

number of compliers across the district since not all recorded compliers would have been directly observed and not all areas achieved consistent compliance rates; this research may also provide insights for the improvement of compliance rates in those areas in Alor which did not achieve a high compliance rate.

# CHAPTER 1: BACKGROUND AND REVIEW OF LITERATURE

---

## 1.1. LYMPHATIC FILARIASIS

Lymphatic filariasis (LF) is one of the oldest parasitic diseases in the world. There is evidence of its presence in Egyptian statues from 2,000 BC and in ancient medical texts from China, India and Persia (Dean 2001). Today, LF affects more than 120 million people worldwide and over one billion persons live in areas at risk for infection (Ottesen et al. 1997; Goldman et al. 2007). LF is an important public health and socio-economic problem facing developing countries. Filariasis does not kill, but rather disables those who develop long term clinical manifestations of the disease. Moreover, LF has been recognized as the second leading cause of permanent and long-term disability in the world, affecting primarily those in poverty (WHO 1999). This disfiguring condition not only affects working ability, but also causes stigmatisation and anguish particularly for those with elephantiasis<sup>1</sup>; inhibiting their chances for marriage and increasing stigma and social exclusion (Wijesinghe et al. 2007).

There are three types of LF: *Wuchereria bancrofti*, *Brugia malayi* and *Brugia timori*. *W. bancrofti* is responsible for 107 million infections and brugian filariasis, 13 million infections (Ottesen et al. 1997). *B. timori* is only found in Indonesia and in East Timor (Simonsen 2003).

Patrick Manson discovered the mosquito as the key agent in the transmission of LF to humans in 1877 (Dean 2001). When the female mosquito feeds on a human victim, it ingests blood and, if the person is infected with LF, microfilariae (mf). Once inside the mosquito's body, the mf take between 10-20 days to develop into infective larvae (L3). Once matured, these L3 larvae make their way from the mosquito's stomach to its mouth. During the mosquito's next feeding, the larvae

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<sup>1</sup> Severe or advanced lymphoedema, which is defined as swelling caused by the collection of fluid in the tissue. Dreyer, G., D. Addiss, P. Dreyer, et al. (2002). Basic Lymphoedema Management: Treatment and Prevention of Problems Associated with Lymphatic Filariasis. Hollis NH, Hollis Publishing Company.

crawl onto the skin and try to enter the body through the hole made by the mosquito.

After entering the blood stream, the larvae move to the lymphatic system where they develop into thread-like adult worms in 3 to 12 months. Adult worms live in nests containing on average 2-3 worms and mate there. Females grow to 10 cm and males to 4 cm<sup>2</sup>. During the course of their lifetime (up to 7 years), male and female worms reproduce creating millions of microfilariae. These microfilariae enter the peripheral bloodstream from where they may be taken up by a biting mosquito, thus perpetuating the disease cycle. All three filarial species (*B. malayi*, *W. Bancrofti*, *B. timori*) demonstrate periodicity; which is dependant on the biting habits of the mosquitoes and on the concentration of mf in the peripheral blood of the host. In most areas the periodicity of *B. malayi* and *W. bancrofti* is nocturnal, with mf concentrations in peripheral blood peaking at around midnight<sup>3</sup>. (Dean 2001; Simonsen 2003)

The adult worms gradually damage the lymphatic system, by interrupting the passage of the immune fluid throughout the lymphatic system. As a result, the circulation of immune cells needed to clear an infection is hampered, causing swelling to the reproductive organs and limbs. When the adult worm dies, it continues to obstruct the system. (Dean 2001) Primary clinical features of bancroftian filariasis, the most widespread, include acute adenolymphangitis (fever, chills, malaise, pain in the lymph nodes), hydrocele (swelling due to collection of fluid around the testicles), lymphoedema and elephantiasis, chyluria (presence of chyle in the urine) and tropical pulmonary eosinophilia (syndrome of immunological response to mf in the lungs). Brugian filariasis rarely presents the clinical features of hydrocele or chyluria and; elephantiasis is usually restricted to below the knee. (Simonsen 2003)

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<sup>2</sup> Adult *Brugia* species are half as large.

<sup>3</sup> Because of its nocturnal periodicity, public health interventions which want to evaluate the endemicity in an area will take blood samples at night (termed night blood) when the mf are at the periphery.



Unlike malarial parasites, LF parasites have low transmission efficiency; that is, the probability that a bite by a mosquito carrying L3 filarial larvae will lead to an eventual human infection is low. (WHO 2002) L3 development within the mosquito and transmission to another human must occur within the mosquito's 7-21 day life cycle (Dean 2001). Inefficiency of transmission makes LF an attractive disease for attempts at elimination.

## **1.2. EPIDEMIOLOGY OF LF IN INDONESIA AND**

### **ALOR**

LF was first reported in Indonesia in 1889 (Oemijati 1999). All three types of LF exist in Indonesia: *B. malayi*, *B. timori*, *W. bancrofti*. Among the primary vectors for transmission of LF in Indonesia are *Anopheles barbirostris* (Putrali et al. 1975; Partono et al. 1978; Partono and Purnomo 1985), *Mansonia uniformis* (Oemijati et al. 1986), *Mansonia annulata*, *Mansonia bonneae* and *Mansonia dives* (Suzuki et al. 1981), *Culex quinquefasciatus* (Oemijati 1999) and *Anopheles subpictus* (Supali et al. 2002).

Alor District has only two types of LF, *B. timori* and *W. bancrofti*. A survey in a highland area of Alor in 2002 showed a standardised population prevalence of 25% of mf carriers (for *B. timori*). The highest prevalence of mf positive persons was in men and women between 40 and 50 years (50% men and 38% women). (Supali et al. 2002). Surveys conducted by the District Health Authority from 1996-2000 showed that mf rates for *W. bancrofti* and *B. timori* ranged from 1.7 – 11.9% in 17 villages on Alor (*Dinas Kesehatan Kabupaten Alor*). Due to vector breeding behaviours, *B. timori* filariasis is more prevalent in rice-growing areas and *W. bancrofti* filariasis is more prevalent in coastal areas (Supali et al. 2002).

Economic analysis of LF in five provinces in Indonesia (including Nusa Tenggara Timur province) demonstrated that on average a person with chronic LF spends 735,380 IDR (\$79 USD) per year as a result of their infection: 157,496 IDR (\$17 USD) on treatment costs; 306,000 IDR (\$33 USD) due to loss of productivity; 236,244 IDR (\$25 USD) due to time loss for care of chronic cases

and 35,640 IDR (\$4 USD) for non-treatment related medical costs<sup>4</sup>. This represents 67% of the total household expenses for a family living in poverty, and between 16% - 30.5% for a wealthier family. (Gani 2000) Based on Professor Gani's analysis, the economic justification for LF elimination in Indonesia is clear.

### **1.3. THE GLOBAL PROGRAMME TO ELIMINATE LF**

In 1998, the Global Programme to Eliminate LF (GPELF) was created, with a target of LF elimination by 2020. GPELF uses a two pronged approach for elimination, combining mass drug administration (MDA) for all those eligible in at risk populations<sup>5</sup> (Ottesen et al. 1997) with assistance for those with elephantiasis in order to reduce and prevent further swelling (Dreyer et al. 2002). Thus far in the elimination campaign, by 2006, over 400 million people in half of the 83 endemic countries have taken the recommended mass drug administration (Gyapong and Twum-Danso 2006; Goldman et al. 2007).

Present challenges to GPELF targets include convincing asymptomatic persons to take the treatment (Partono et al. identify as a key determinant of success the degree of participation by asymptomatic carriers (Partono et al. 1989)); maintaining sufficient coverage and compliance over the required 4-6 year period; and the potential for deterrence created by possible side effects in both symptomatic and asymptomatic persons. These challenges continue to surface as the GPELF expands globally. Some evidence indicates that coverage levels in certain areas are insufficient for elimination despite varied interventions (Ramaiah et al. 2000; Ramaiah et al. 2006; Regu et al. 2006).

In the past, efforts to control LF have focused on 12-day or 40-week selective treatment regimens with diethylcarbamazine (DEC); some programmes adding vector control in order to further interrupt parasitic transmission (Alexander 1987; Maxwell et al. 1990; Ottesen et al. 1997; Cave and Curtis 1999; Maxwell

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<sup>4</sup> Usually, when someone is hospitalized, the hospital charges for non-drug related fees, such as fees for the doctor's visit, fees for treatment (operation or otherwise). (Personal communication with Mrs. Heny Nggadas)

<sup>5</sup> Pregnant women and children under 2 years of age are generally excluded from MDA.

et al. 1999). Treatment was selective, and required individuals to be tested using thick blood smears before treatment. More recently with the introduction of GPELF, control has focused on treating the entire population through mass drug administration, an approach which avoids blood examination and requires a large proportion of the population in endemic areas to take treatment without diagnosis.

MDA has several advantages over selective treatment: (1) night blood examinations are no longer necessary, reducing costs and pressure on health staff and communities; (2) MDA is more cost effective, especially when integrated with existing anti-helminth and other public health campaigns (Beach et al. 1999; Molyneux and Nantulya 2004); (3) the risk of false negative results of blood smears is removed (Partono 1984); (4) the chance of not treating an infected person is reduced; (5) positive side effects of co-administered treatment with Albendazole include clearance of other types of intestinal helminths (Ottesen et al. 1999; Padmasiri et al. 2006) and, with Ivermectin, the control of head lice (Beach et al. 1999).

MDA eliminates microfilariae using a single annual dose as follows: Albendazole and diethylcarbamazine (DEC) in those areas where onchocerciasis and loiasis are not co-endemic with LF, and Ivermectin alone where they are (Ottesen et al. 1997; Ottesen et al. 1999; Borsboom et al. 2003). These drugs significantly reduce microfilariae loads in the blood and can kill up to 50% of adult *W. bancrofti* worms (Ottesen et al. 1997). The drug treatment offers some relief for those with lymphoedema, especially when coupled with specific management to reduce swelling (Ottesen et al. 1997; Dreyer et al. 2002). Vector control also remains an important component to the elimination programme by preventing re-infection of people whose pre-existing infections have been successfully treated (Cave and Curtis 1999; Reuben et al. 2001).

Adverse reactions to treatment with DEC alone and with DEC/Albendazole are not life threatening. The severity of the reaction increases with the density of the microfilariae (Sutanto et al. 1985; Jayakody et al. 1993; Supali et al. 2002;

McLaughlin et al. 2003). As a result, side effects are more common in the first year of treatment when microfilariae levels are high. In a pilot treatment survey in Alor District conducted by Supali et al (2002a), fever was experienced by those infected with either *W. bancrofti* or *B. timori* and generally occurred 12-24 hours after treatment. In a larger survey of over 70,000 persons in Haiti, 24% reported one or more adverse reactions, with 2% reporting reactions severe enough to interfere with daily activity (McLaughlin et al. 2003).

In order for mass drug distribution campaigns to be effective in stopping parasite transmission, annual single dose treatments are required for 4 - 6 years, depending on the epidemiology of the endemic area and compliance rates achieved. The aim of mass treatment is to reduce rates of infection of mosquitoes with stage L3 larvae below the level sustaining human infection. There is some debate on the compliance required for elimination. The aim is to treat the entire at-risk eligible population living in endemic areas, with pregnant women and children under 2 years old being excluded (Ottesen 2000). It is thought that treating between 75-80% of the total population each year during the 4-6 year period is sufficient (Ottesen et al. 1997; Babu and Satyanarayana 2003). More studies on mosquito infection rates after MDA are needed to determine with certainty the percentage treated required in the population to achieve elimination. One study from India has shown a reduction in vector infection and infectivity of over 89% after 10 rounds of MDA (Ramaiah et al. 2007).

Achieving high compliance globally in endemic communities is challenging. Therefore in order to improve compliance, current recommendations for LF elimination campaigns include the use of the COMBI method, Communication for Behavioural Impact, as a precursor to MDA (WHO 2003). COMBI differs from traditional IEC by moving beyond generating awareness to encouraging behaviour change. It combines social mobilisation and social marketing approaches with a disease-oriented behavioural focus. (Parks and Lloyd 2004) Reception of COMBI has been mixed – with experience showing that it is expensive (Malecela-Lazaro and Twum-Danso 2004) and though it can increase coverage, it has not proved universally effective in achieving compliance at

sufficient levels to sustain elimination (Ramaiah et al. 2006). Experiences in Zanzibar, however, have shown COMBI to have a positive impact on compliance (Thompson 2002). Critics of COMBI claim that it is selling to the poor in the developing world health interests which have been fabricated for them in wealthy industrialised nations (Banerji 2004). Despite its mixed reception, COMBI is currently the recommended socialisation method for MDA by the GPELF.

#### **1.4. MASS DRUG ADMINISTRATION IN INDONESIA**

Advances have been made in the elimination of LF in Indonesia, some of which can be attributed to medical and health services interventions (DEC administration), while others have resulted from the removal of the vector through urbanisation and the cultivation of swamplands. (Oemijati 1999). Despite these advances, areas of high endemicity remain throughout the country.

The Indonesian LF elimination programme, or ELKAGA (*Eliminasi Kaki Gajah*), began in 1970. In the early days of the MDA programme, health services used low dose treatments for varying periods, among them: 6 days (Putrali et al. 1975), 9 days (Partono et al. 1979), 12 days (Oemijati 1999), and 6 months (Partono and Purnomo 1985). The results of these initial treatment programmes revealed high rates of adverse reactions. In a mass treatment trial using DEC in Central Sulawesi, in 7930 inhabitants receiving the drug, 19-51% of patients experienced fever with or without vomiting (Putrali et al. 1975). A study of 15 microfilaraemic patients with *B. malayi* in 1985 cautioned that although adverse reactions were not life threatening, they were severe enough for some patients to spend 48 hours in bed, with consequent disruptions to individuals' lives and the economy of the area (Sutanto et al. 1985). Anecdotal evidence from Buru Island revealed that a medical team was nearly killed after returning to the area 6 months after initial treatment, due to the inhabitants' inability to work for 2 months after receiving treatment (mf prevalence had been 43%) (Oemijati 1999). In Alor District, Supali et al (2002) showed that all 30 patients monitored with *B. timori* reported side effects post-treatment, although none severe or life-

threatening. In the same study, 59% of patients with *W. bancrofti* (n=27) reported side effects (Supali et al. 2002).

Past experiences and research with low dose treatments have had mixed results in Indonesia and consequently, there was the widespread concern about the risk of side effects which led to reluctance on the part of the Department of Health (*Departemen Kesehatan RI*) to agree to the GPELF recommended mass drug administration with DEC and Albendazole. However in 2002, they agreed to move forward with this policy, largely based on the pilot study results from Alor District which showed positive results of MDA with DEC and Albendazole following a comprehensive socialisation campaign (Krentel 2004).

According to the last report from the National LF Programme (2005), 170 endemic areas have been identified for MDA representing a total population of over 9 million people. Presently 55 of those areas have begun MDA (The National Programme to Eliminate Lymphatic Filariasis 2005). In 2007, Alor will complete the 6<sup>th</sup> round of MDA. Recent results for the Alorese programme show that Alor is close to achieving LF elimination (Table 1).

**Table 1 Evaluation of MDA in Alor Island**

Evaluation for MDA in Alor Island		Pre MDA	2002	2003	2004	2005	2006
1.	Compliance for MDA		86,5	92,5	89,1	96,9	90,6
2.	Mf rate	25	17	6	4	3,3	0,3
3.	Hydrocele operation			24		9	

(Source: GTZ SISKES)

Table 1 shows that compliance in Alor District has been sufficient to reduce mf rates in Alor from 25 before the programme began to <1% in 2006. In my opinion, the compliance rates reported here reflect a combination of both compliance and coverage. Compliance is defined as actually swallowing the pills and coverage is the distribution of the pills to the population. Because in some areas, health personnel would have observed population members swallowing the pills, their records indeed reflect compliance; while in other areas, health personnel would have distributed the pills to the household in faith that they

would comply with the treatment later – their records reflect coverage. Furthermore, when considering that in a total population, all pregnant and breastfeeding women and all children under the age of 2 are not eligible for MDA, a compliance rate of over 96% would be impossible.

## **1.5. COMPLIANCE WITH LF TREATMENT**

Challenges to the success of the GPELF are strongly related to sustained compliance with mass administrated treatment. An understanding of documented factors associated with compliance, is essential in order to identify where further research is needed.

### **1.5.1. ISSUES OF TERMINOLOGY**

Conventionally the term compliance has been used in the literature regarding MDA for LF (Kasturiratne et al. 2001; Babu and Satyanarayana 2003; Babu and Kar 2004). In recent years, however, in public health, there has been a shift away from the use of the term ‘compliance’ towards terms like ‘concordance’ and ‘adherence’ in order to show the patient’s interaction with medicine-taking in relation to illnesses like diabetes, hypertension and other chronic conditions. In 1997, the Royal Pharmaceutical Society of Great Britain recommended using the term concordance in preference to compliance when describing a patient’s medication-taking behaviour (1997). The grounds for the change relate to compliance being seen as a limiting term – associated with following doctor’s orders (Evans et al. 2001), being paternalistic (Rossi 2000) or implying deviance when medical advice is not followed (Horne et al. 2005). “... Compliance refers to the extent to which patients follow doctors’ prescriptions about medicine taking.” (page 87) (Horne et al. 2005) Concordance, on the other hand, denotes communication and cooperation between patient and practitioner and assumes that at the end of the consultation they will have reached a mutually beneficial goal where the patient takes the medication as prescribed (Evans et al. 2001). Use of the term concordance lessens the sense of blame or judgment by the health care provider; suggesting negotiation and open discussion.

The Royal Pharmaceutical Society describes concordance as being:

“...based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them.... Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment” (page 498) (Bissell 2003)

Concordance implies comprehensive communication between doctor and patient about the treatment regimen. In the case of MDA, however, there is no diagnosis before LF treatment is distributed, so those asked to take the medication are not necessarily infected and are less easily described as patients. Secondly, the nature of LF treatment in the form of MDA also limits the amount of discussion between provider and patient. Compliance is considered to be a more appropriate term than concordance in clinical trials; in some cases of personal behaviour (like depression); and where the patient has an infectious disease, like multi-drug resistant tuberculosis, which if he does not seek treatment, will cause harm to others (Milburn and Cochrane 1997).

According to a NHS report on the subject, adherence inherently gives the patient freedom to choose and relieves him of any blame if he chooses not to follow the prescriber’s instructions or recommendations (Horne et al. 2005). Adherence has been described as appropriate in a context in which “...the provider weighs the diagnosis and therapies in terms of risk and benefit, makes a decision, informs the patient and assumes the patient understands and will adhere” (page 5) (Wahl et al. 2004). Wahl et al. (2004) relate adherence to chronic diseases, like coronary heart disease or AIDS, where patients must achieve a high percentage of adherence (80% and 95% respectively) to receive benefit from the treatment. Given the long term nature of therapy associated with adherence, it would seem an appropriate term for use in the context of LF. Again however, the degree of provider–patient communication required to encourage adherence as well as the necessity of a diagnosis and prescribed therapy, raise doubts about its appropriateness to LF.



Bearing in mind these considerations, compliance appears to be the most fitting term for use within the context of MDA for LF. There is no pre-requisite diagnosis or discussion about treatment plans; rather the patient is asked to follow the doctors' recommendation. Furthermore, often it is not doctors or even health professionals who distribute LF drugs and it would be difficult to describe all individuals as patients, since many will not be infected with LF and if they are, may not be aware of the fact. The somewhat negative descriptions of compliance from Rossi (Rossi 2000) (as paternalistic) and Horne (Horne et al. 2005) (as implying deviance when there is a failure to comply) could indeed express some of the elements of its use in MDA; e.g. a certain degree of paternalism involved as people are asked to trust those in authority that the LF drugs are necessary and an implied deviance for non-compliers as they could be seen as harbouring LF.

For these reasons, I decided to use the term compliance to describe the process of taking the required medication for lymphatic filariasis (LF).

### **1.5.2. FACTORS ASSOCIATED WITH COMPLIANCE**

Few studies identify factors associated with compliance with LF treatment and even fewer studies, to my knowledge, have looked qualitatively at the influences individuals report when complying with mass treatment. Most studies examining these factors associated with compliance use quantitative data from knowledge, attitudes, practice and behaviour (KAPB) surveys.

Socio-demographic factors found to be associated with compliance include sex (being male) (Mathieu et al, 2004) and educational level (Kasturiratne, Premaratne et al. 2001). In an Indian study, compliance rates were lowest among the most, and the least, educated. The authors conjecture that the most highly educated could have been sceptical of free medicine while those with less education may not have understood what the drugs were for.

Awareness of LF and information about its transmission have also been shown to be associated with compliance. A recent study (Ramaiah et al. 2006) of the use of COMBI methods in the state of Tamil Nadu showed that there was a fairly high

level of drug consumption by those who had been most exposed to the media campaign and who had been visited by a local drug distributor. In a KAPB survey following a pilot study on mass drug administration in Haiti, factors associated with taking LF treatment included knowing that LF is mosquito-borne and having received a LF related message through posters or banners (Mathieu et al, 2004). The authors concluded that health messages which explain the nature of LF motivate people to comply with treatment (Mathieu et al. 2004). Similar conclusions were reached by Ahorlu et al (1999) who recommended development of comprehensive health education messages to motivate individuals to comply. (Ahorlu et al. 1999) These three studies suggest that awareness and knowledge of the disease motivates individuals to comply.

A preliminary KAPB survey to assess knowledge and attitudes in a Haitian community prior to treatment intervention found that the majority, 95% of those asked, would take treatment for LF if it were offered to them, regardless of their infection status (Eberhard et al. 1996). This may reflect willingness to comply with treatment simply because it is available and offered to them, rather than specifically to cure LF. Similarly Rao et al. compared the outcomes of mass treatment and selective treatment in diagnosed microfilariae (mf) carriers, and found coverage was twice as high (90%) among the total population as it was in selective treatment for mf carriers (coverage was low (45%)) (Rao et al. 1986). In the selective arm, individuals were not motivated to comply because they were infected, suggesting that there were other factors at work which inhibited their participation. (Sunny et al. 1984)

The evidence also suggests that additional health benefits of intestinal helminth elimination may encourage compliance (Beau de Rochars et al. 2004). In areas in which Albendazole and DEC are used, participants benefit from a reduction of intestinal helminths, namely *Ascarius*, *Trichuris* and hookworm. Evidence from this paper shows that even non-participating members in the community (pregnant women) benefit additionally from the protective effects of an overall reduction in intensity of helminths created from community-wide participation.

Where information is provided about adverse reactions, the evidence is that they may be interpreted as an encouraging sign that the drugs are working, since people will understand that they are a result of the death of microfilariae. In Orissa, India, improvement in coverage rates was attributed to effective communication about adverse reactions (Babu and Kar 2004). Shu et al report similar conclusions from a Nigerian onchocerciasis programme where villagers were informed about adverse reactions and correctly interpreted them as a positive sign of the drugs' efficacy. (Shu et al. 1999) Anecdotal evidence from the GTZ directed pilot programme in Alor District showed similar findings (Krentel 2002).

Inclusion of local leaders and their acceptance and advocacy of the treatment programme has been shown to be essential in promoting community awareness (Partono 1984). If local leaders are reluctant to support or are unsupportive of the treatment programme, then compliance can be negatively affected (Ramaiah et al. 2001). Leaders can ensure that people's perception of the drug distribution is positive and considered as good welfare from the government (Ramaiah et al. 2000).

Like the LF elimination programme, the onchocerciasis elimination programme relies on community participation and in communities where the kinship/clan structure is weakened, for example, in urban areas, programmes have been found to suffer (Katabarwa et al, 2000). Rural communities in Uganda using a distribution system based within the clan system achieved a 94% coverage rate compared with only 71% in urban communities ( $p=0.028$ ). Reasons for the difference in rates were attributed to the more complicated lifestyles and demands placed on urban families as well as their lack of connection with the traditional structure of the clan system. The authors discuss the benefit of using the kinship system for distribution and control of the programme, mentioning the importance of traditional laws, positive perception of receiving tablets from an insider

(versus an outsider), social code governing drug distributors and counselling for sufferers of adverse reactions from group leaders. (Katabarwa et al. 2000)

### **1.5.3. FACTORS HINDERING COMPLIANCE**

The literature suggests that factors inhibiting compliance with LF treatment fall into four broad categories, relating to adverse reactions to treatment, programmatic issues, lack of community involvement and failure to perceive LF as a personal risk.

#### **Adverse reactions**

Although life threatening adverse reactions have not been reported globally, minor reactions and those which interfere with daily activity have been cited in the literature as reasons for non-compliance. Despite their possible role in persuading people of the effectiveness of MDA, adverse reactions to DEC have been shown in the early studies from India and Indonesia to have negatively affected compliance as individuals were not aware of them (Putrali et al. 1975; Partono et al. 1979; Partono et al. 1981; Partono and Purnomo 1985; Sutanto et al. 1985).

In a recent evaluation of the LF programme in Orissa, India, (Babu and Kar, 2004) fear of adverse reactions emerged as the most common reason, given by 82% of respondents, for not taking anti-LF drugs. The relatively low coverage and compliance rates in Orissa were attributed to the magnitude of adverse reactions, among other factors. In a more recent study in Kerala State, 25% reported fear of adverse reactions as the reason for not complying, despite adverse reactions being minimal (Regu et al. 2006). In another study, rumours of severe reactions discouraged community members from participating in future treatment rounds (Mathieu et al. 2004). In one Indian study, 66% of those who refused treatment did so because of possible side effects (Jain et al. 1986). In another Indian study, 28% of those who refused to swallow the tablets reported a fear of adverse reactions (Babu and Satyanarayana 2003). A recent qualitative study of a MDA in Papua New Guinea confirmed that people refused treatment in order to avoid suffering from vomiting, drowsiness or dizziness associated with

treatment (Wynd et al. 2007a). These studies show that adverse reactions can have a significant effect on coverage and compliance.

### **Programmatic issues**

Motivating and sustaining compliance relies on a well-organised, sustainable and accessible distribution process throughout the duration of the elimination programme. The literature contains evidence of a number of programmatic issues which may affect coverage. These include: procurement delays, unclear, inadequate or under-developed processes for distribution (of both drugs and IEC materials), general factors affecting rural district health services (decentralisation, staff shortages, overburdened staff, lack of operational funds) and political issues at village or district levels. In a systematic evaluation of MDA in India, Babu and Kar (2004) reported interruption of MDA at local level as a result of delays in the drug supply; 76% of those who did not receive drugs (n=4556) reported that the drug distributor did not visit their household. In another evaluation study in India, 53% of those who did not receive tablets reported that the health worker or distributor had not visited them (Babu and Satyanarayana 2003). Another survey confirmed that a major cause of non-compliance was difficulty in obtaining the drug from the distribution sites (Kasturiratne et al. 2001). In the COMBI evaluation by Ramaiah et al. (2006), the authors reported that in some primary health care centres, IEC materials were received only a few days prior to the start of the distribution, making it difficult to use them in advance as planned.

Depending on region, different techniques have been used for drug distribution which balance or combine community directed and health services directed approaches (Partono et al. 1984; Sunbramanyam Reddy and Venkateswaralu 1996; Whitworth et al. 1996; Meyrowitsch et al. 1996a; Meyrowitsch et al. 1996b; Mohammed et al. 1998; Oyibo and Fagbenro-Beyiku 1998; Ramaiah et al. 2000; Gyapong et al. 2001; Ramaiah et al. 2001; Bockarie et al. 2002; Katabarwa et al. 2002; Krentel 2002; Babu and Kar 2004). In some areas in India, compliance has been shown to be lower in areas where communities directed the treatment than in those areas where the health services administered treatment (Ramaiah et al. 2001). In a study in Ghana, the community directed approach

combined with a health services approach was shown to be more effective for enhancing compliance in the community than the health services approach alone (Gyapong et al. 2001). Some of the difference in these results can be attributed to cultural factors and highlight the importance of understanding the local socio-cultural setting.

In some areas in which community directed approaches to drug distribution have been used, encouraging village health workers has been considered to be a slow process needing constant persuasion and “strong measures” (page 372) to persuade villagers to achieve programme goals (Partono et al. 1984 page 372). In other cases un-cooperative and sometimes hostile community responses have apparently made health workers reluctant to participate in the treatment programmes (Hyma et al. 1989).

Health workers’ knowledge of the disease, treatment and side effects may also have consequences for compliance. In a pilot study in India, health workers were unaware of the possibility of side effects post-treatment and did not warn the community. As a result, people’s confidence disintegrated after side effects arose and it was a further three years before mass treatment could be resumed. (Babu and Satyanarayana 2003) Furthermore, there is evidence that people in the community do not always trust their fellow community members to give them treatment (Ramaiah et al. 2006).

### **Community involvement**

The case has been made for greater community awareness to enhance compliance and overcome some of the issues mentioned above (Shu et al. 1999; El Setouhy and Rio 2003; Suma et al. 2003; Babu and Kar 2004). The early phase of the National Filaria Control Programme in India (1955-56) failed due to a lack of adequate health education in the community (Jain et al. 1986; Krishna Rao et al. 1986) and the Indonesian LF programme suffered from a lack of clear social mobilisation in the community (Oemijati 1999).

The assumption is made that awareness in the community should promote community involvement, considered to be the backbone of LF elimination (Katabarwa et al. 2000). Globally, social mobilisation and COMBI are promoted as a means of increasing treatment coverage (Riji 1986; Ahorlu et al. 1999; Ramaiah et al. 2000; Kasturiratne et al. 2001; Ravindran 2002; Babu and Satyanarayana 2003; Suma et al. 2003). Social mobilisation has been defined as:

“[Engaging] people’s participation in achieving a specific goal. It involves all relevant segments of society: decision and policy makers, opinion leaders, non-governmental organizations such as professional groups and religious groups, the media, the private sector, communities and individuals. It is a process of dialogue, negotiation and consensus for mobilizing action that engages a range of players in inter-related and complementary efforts, while taking people’s needs into account.” (Stimson et al. 2003[http://www.who.int/docstore/hiv/Core/Chapter\\_6.html](http://www.who.int/docstore/hiv/Core/Chapter_6.html))

Although there is evidence that social mobilisation improves compliance in the first year of MDA, there is scant information on its impact in the longer term, since evaluation studies have largely focussed on the first year of the MDA. Recommendations have been made that these campaigns should be specific to cultural contexts (Gyapong et al. 1996; Suma et al. 2003) and include socio-cultural research as a backbone to their programmes (Wynd et al. 2007c). Yet there is little evidence of systematic work on people’s perceptions and understanding of LF treatment and possible adverse reactions which would enable campaigns to be better adapted to the community (Whitworth et al. 1996).

Community involvement seems more difficult to achieve in urban areas where local government and relevant stakeholders are less accessible. In some countries, failure to control LF in urban areas could be prohibitive to the overall nationwide success of the programme. In India for example, one third of the LF burden is in urban areas (Sunny et al. 1984).

### **Limited perception of risk for LF infection**

Research shows that people fail to comply with treatment because they do not consider LF to be a risk or a problem for them. In Papua New Guinea, Wynd et

al. (2007) reported that some individuals no longer saw LF in their area, and so were not aware of any treatment. Furthermore, 43% of those monitored after a MDA in Kozhikode District, Kerala, India reported not taking the drug because they saw no disease, so therefore thought it was unnecessary (Regu et al. 2006). In a related study, participants in a qualitative evaluation of a MDA in Tamil Nadu were confident they would not be infected by LF while others reported similarly being in good health and therefore did not need the drug (Ramaiah et al. 2006). Rath et al. (2006) reported that perception of risk in the study communities in Orissa, India was low, due to their lack of knowledge about the transmission as well as the fact that they were not observing many lymphoedema cases in their communities.



## **CHAPTER 2: RATIONALE FOR FURTHER RESEARCH**

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### **2.1. ACCORDING TO THE RESEARCHER'S EXPERIENCE**

At the time I enrolled as a PhD candidate in the autumn of 2003, I had already spent a considerable amount of time living and working in Indonesia and Alor District. I first came to Indonesia in 1999 to work with Médecins sans Frontières in West Timor Island. During this time, I took Bahasa Indonesia lessons and became acquainted with the culture and peoples of eastern Indonesia. In 2002, after one and a half years working in West Timor, I began a long term consultancy appointment with the German Technical Cooperation (GTZ) SISKES project (2002-3), which focused on strengthening the district health systems in two districts, Alor and East Sumba. My role was to develop a comprehensive control programme for LF elimination in 6 pilot villages in Alor as an example for the national ELF programme which we hoped would lead to a change in national policy to accept the use of a single dose regimen of Albendazole and DEC according to the GPELF guidelines for MDA.

As a result of this appointment, I spent a considerable amount of time in 2002 in Alor travelling throughout the islands, in particular to the 6 pilot villages and working together with community leaders and district health officials to set up and implement the MDA. During this time, I learned about the culture of Alor, observing first hand how different communities interacted and related to the MDA. Of the six villages, three were endemic for LF.

The pilot project allowed each of the six communities to develop together with their community leaders the most appropriate method for drug distribution – through house visits, after church meetings or during community meetings. As a result, this degree of autonomy allowed me to observe how different village leaders presented the MDA to the communities and how people responded to the drug distribution. These observations and experiences helped to shape some of

the questions which guide this research. For example, one midwife in an endemic village told me that she went house to house to inform people of the upcoming treatment, telling them that if they did not comply with the treatment, they might as well move out of the village; as they would potentially harbour the disease. I saw the importance of respecting the village leader and what befalls you without their support. I observed how a village runs when the head of the village is weak and which parties step in to assume the leadership. I also saw the power of one village leader who had a reputation for strong black magic and the influence that had on his community and their obedience to him. I also witnessed during the MDA campaign how willing people were to come forward to a meeting place and take pills directly in front of the health workers and the rest of the community, despite having only limited exposure to the campaign.

In addition to these observations, I also conducted three KAPB surveys to measure the impact of the pilot campaign. My observational insights as well as the data collection carried out during the pilot project led me to believe that there were elements influencing compliance in Alor which were as of yet unstudied and undocumented. Furthermore, I thought about the reasons why people would want to comply with treatment which may make them sick (from side effects) when they suffered no present effect of the disease. I realised that a similar campaign would probably fail in western societies. What then makes places like Alor different? Why were we able to convince people to comply with treatment, at a potential detriment to their immediate health? What factors were at work within these communities and within individuals to make them agree to comply? I felt that the answers to these questions would benefit the global initiative to eliminate the disease and may lend understanding to other areas in Indonesia and in other parts of the world where compliance rates may be unsatisfactory.

## **2.2. ACCORDING TO PRELIMINARY RESEARCH**

In October and November 2004, I conducted a KAPB survey<sup>6</sup> one month after the third round of MDA in Alor District as a preliminary measure to assess some

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<sup>6</sup> The fourth of its kind in Alor; for this one I added some open ended questions which would allow the respondent to answer more freely about people who influenced them, for example.

of the factors thought to be associated with compliance with MDA. Namely, I wanted to seek out associations between individual characteristics and knowledge and perception of risk as these are fundamental precursors to behaviour change in many of the behaviour change theories. Besides concentrating on the individual-related factors, I also wanted to investigate the presence of group-related factors such as observational learning (in the social cognitive theory) and the presence of subjective norms and normative beliefs (theory of reasoned action and planned behaviour). In order to test the premises of the Health Belief Model in particular, I looked for associations between reported compliance and knowledge-related questions (perceived susceptibility), compliance and perception of LF as a problem (perceived seriousness) and compliance and knowledge of treatment (knowledge of potential benefit).

For the purposes of this KAPB research, I used a fully structured fully scheduled questionnaire with a few open-ended questions which were back coded during analysis. (See Appendix A.2. for full methodology) I will briefly discuss some of the research results and the associations which arose out of the data which suggested that further research into this area was warranted.

Out of 207 people who reported receiving the drugs (out of a total of 384 people), 8 people did not take the treatment and there is a missing value for one person. The following table outlines those results with Pearson's Chi-square tests for significance.

Table 2 KAPB preliminary results (2004)

	From KAPB survey questions, of those who received the drug (n=207)	Complied with treatment (n=198)	Did not comply with treatment (n=8)	Fisher's exact test results & p values (two-tailed)
1	Has heard of <i>filaria</i>	184 (93.88%)	8 (100%)	0.61 (p=1.00)
2	Has heard of <i>kaki gajah</i>	179 (90.86%)	5 (62.5%)	6.28 (p=0.0418)
3	Has heard of <i>boa besar</i>	155 (79.08%)	4 (50%)	3.49 (p=0.0817)
4	Knows LF is transmissible	139 (70.56%)	6 (75%)	0.08 (p=1.00)
5	Knows LF is caused by worms	28 (14.21%)	0	1.31 (p=0.6018)
6	Knows LF is caused by mosquitoes	95 (48.22%)	1 (12.5%)	3.89 (p=0.0700)
7	Thinks LF can be treated	181 (91.88%)	8 (100%)	0.75 (p=1.00)
8	Perceives LF to be a problem	161 (81.73%)	6 (75%)	0.20 (p=0.6479)

In reviewing table 2, it appears that knowledge (lines 4, 5, 6) has no significant association with compliance. Rather, awareness of one local name of the disease (*kaki gajah*) has only a borderline association with compliance ( $p=0.0418$ ). Neither knowledge of potential treatment nor perception that LF is a problem is strongly associated with compliance. In light of these findings, it seems that there must be other factors at work in this sample, besides the tenets laid out in the Health Belief Model, for example.

To investigate the possibility of other factors at work, examination of preliminary results of the open-ended questions revealed some new themes permeating the motivations people expressed for complying with treatment. These themes came from analysis of two specific open-ended questions: "Why would someone want to take the LF treatment?" and "Why did you agree to take the treatment?"

My supervisor Professor Kaye Wellings and I separately examined responses to the open ended questions and categorised the emerging themes. Inter-rater reliability was high, and we both independently derived categories of 'external'

or 'other' directed and 'internal' or 'self' directed. As the terms suggest, 'external' refers to those forces outside of the individual which motivate him whilst 'internal' refers to those forces which come from within the individual. Individual characteristics (position within society, gender, age, socioeconomic status, education) may also affect how the individual reacts to different influences at work.

External determinants come from outside of the individual. They require a social structure to be in place, and for an individual to be aware of it and attend to it in order for external motivations to be psychologically present. They include punishment or sanctions to the individual if he does not comply with treatment. Comments included, "*the head of the village was angry with us so we took the drugs quickly*" and refer to the importance of the power of village leaders in motivating people to comply through the threat and/or fear of sanctions.

Questionnaire respondents also referred to health professionals and their forceful and informative influence. Health professionals have been known to say that if people did not take the drugs, then they could not expect medical treatment for other ailments throughout the year (Anecdotal evidence from fieldwork October 2004). Other externally directed influences included expectations to comply from the heads of household. These social norms were also expressed in terms of what the individual expected of his own family members and neighbours.

Internal determinants affect the individual through his understanding of the disease, the drug and its benefits; but they are not limited to health issues only. These influences also reflect the internal values that people may have: happiness, safety, a longer life, a better quality of life, social acceptance, care for others and being a good citizen or member of the community.

For example, individuals mentioned being motivated to take the treatment in order to take better care of their family – specifically economic assistance for immediate members of the family, care for children, or assistance to parents in

the field. Personal gain was also expressed – to be healthy so that they are able to work harder and make more money or to attend school successfully.

Some respondents mentioned that they accepted to take the treatment to protect themselves and those in their immediate environment. One respondent answered, *“So that I am never sick, the family also, the neighbours and everyone I know and friends in the women’s choir at the [Protestant] church.”* No one mentioned the wider district or country in their responses, so relevant social pressures seem to be narrowly focussed.

Social acceptance was also mentioned as a motivation for accepting treatment. One respondent reported that people will be afraid to *“mingle with us”* if they have the disease, whilst another mentioned taking the drugs so that *“I am not ashamed with friends or other people.”*

### **2.3. ACCORDING TO EXISTING LITERATURE**

Sustained and sufficient compliance in the population over the treatment course (4-6 years) is essential to the success of LF elimination globally. According to the literature, individual compliance is dependent on many factors: good programmatic coordination, sufficient communication through social mobilisation and the minimisation of the effect of negative adverse reactions. Furthermore current research has demonstrated that certain factors – demographic, educational, health services related and knowledge-related – are associated with treatment acceptance. In light of my own observations and preliminary research, there is a need for increased understanding of individual reasons for compliance. Increasing knowledge and information is not always sufficient to ensure compliance and there seem to be other factors at work at the individual level. For instance, it is not yet understood how an individual is affected by his membership of a group (village, family and neighbourhood), his own personal values or his emotions. These concepts may explain with greater force why people choose to comply and why they refuse. What is also unknown is how the factors described in the literature (education, gender, socio-economic)

interplay with an individual's personal values, emotions or membership in a group.

## **2.4. AIMS OF THE PRESENT RESEARCH**

Better understanding of individual reasons for compliance will hopefully lead to more effective and improved compliance levels in future MDA campaigns. A recent paper suggests that there is a danger that sufficient compliance levels will not be achieved in present MDA programmes and as a result, the authors recommend adding vector control in order to ensure better long term success of programmes (Burkot et al. 2006). The global LF research community recognises the importance and relevance of this information to the overall success of the elimination effort, now in its 9<sup>th</sup> year; and included in its strategic plan for GPELF supported research a specific call for investigations into motivation and mobilisation to strengthen compliance (Malecela-Lazaro and Twum-Danso 2004). Currently a global evaluation is underway of programme successes and failures and specific focus will be given to socio-cultural perspectives as well as reasons for compliance in an upcoming forum (Personal communication with Professor Eric Ottesen, Director of the Lymphatic Filariasis Support Center).

This study aims to make an original contribution to the existing research on compliance by increasing understanding of the individual reasons for and influences on compliance with MDA for LF elimination. This research intends to make recommendations to the global LF research community as well as to the Indonesian National LF programme in order to strengthen existing efforts to achieve and sustain compliance with treatment.

Specifically, this research aims to:

1. Determine what factors are associated with influencing compliance with LF treatment;

2. Establish what factors are associated with subsequent continuation of, or cessation of participation for treatment for LF;
3. Describe the social and behavioural differences between compliant and non-compliant individuals;
4. Explore the roles of sanctions as possible motivating factors in individual compliance with treatment;
5. Investigate the effect of living in an LF endemic area and describe how that may affect compliant behaviour;
6. Make recommendations based on the results to the global elimination campaign on how to improve and sustain compliance with MDA.



## **CHAPTER 3: THEORETICAL PERSPECTIVES**

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### **3.1. THEORETICAL PERSPECTIVES**

As a basis for the framework for my research, I supposed that the conventional and much used health behavioural models would be central to my theoretical perspective since it is widely assumed that knowledge of the disease, its severity and personal susceptibility and knowledge of risk reduction have an influence on decision-making for health. Before specifying a particular health promotion theory, I reviewed several theories in terms of their construction and suitability for use within the context of investigating individual reasons for compliance.

#### **3.1.1. EXAMINATION OF CURRENT HEALTH BEHAVIOUR THEORIES**

In the 2<sup>nd</sup> Edition of *Health Behaviour and Health Education*, the editors cite the most commonly used theories and models in 497 articles reviewed (Glanz et al. 1997). Based on this list, I have chosen to look at the six most frequently used models which are: Health Belief Model (cited in 100 articles), Social Cognitive Theory (74), Self-efficacy (74), Theory of Reasoned Action and the Theory of Planned Behaviour (66) and Community organisation (50), Transtheoretical model/Stages of change (50). In reviewing each of these models, I will evaluate whether the model would fit the framework for understanding compliance with LF treatment.

##### **Health Belief Model**

The Health Belief Model (HBM) is perhaps the most widely used conceptual framework in health promotion. It was designed in the 1950s by the U.S. Public Health Service in order to explain the failure of people to participate in preventative public health programmes. After sometime, the model became used to relate to people's responses to symptoms, their compliance to medical regimens and then onto wider applications in public health. (Strecher and Rosenstock 1997)

Simplistically, it is based on four perceptions: perceived susceptibility to a problem and perceived seriousness of consequences from that problem which relate to a perceived threat; and perceived benefits of specified action and perceived barriers to taking action, which relate to outcome expectations.

This model is a value expectancy theory, which means in the context of health behaviour that a person desires to avoid sickness and will attempt to get well; and that the action (health behaviour) available to the person will prevent disease or alleviate sickness (Strecher and Rosenstock 1997). The person must feel susceptible to a disease or illness in order to feel that action is warranted to reduce or prevent the disease or illness.

The HBM hinges upon the belief that a person perceives his/her own susceptibility to a condition of ill-health. If a person considers himself/herself to be at risk for this condition, and if he/she feels that the service offered to them will be beneficial, then he/she will begin to take necessary steps towards action. Becker and Maiman (1980) suggest that there is increasing evidence to support the HBM within the context of patient compliance. A patient's beliefs about his/her own health, his/her risk for illness, his/her acceptance of the diagnosis and the viability of the proposed treatment will increase his/her compliance with the treatment (Becker and Maiman 1980). Admittedly, in those villages where LF is present, it is therefore theoretically possible that people without clinical manifestations may feel an increased susceptibility to the infection, which would then put them within the HBM framework towards compliant action. Within this context, a patient's beliefs about his/her own health appear to have more impact on compliance than knowledge about the disease.

Within LF elimination, it is possible that villages where there is no trace of LF must also participate in the MDA. These community members may not perceive themselves to be at risk for an infection that some have only ever heard about and may have never even seen. The application of the HBM in this case is problematic.

In 1977, the concept of self-efficacy was added to the HBM by Bandura (Bandura 1977a; Bandura 1977b; Bandura 1986). Self-efficacy is defined as the confidence that the behaviour required to produce the desired outcomes can be successfully executed (Bandura 1977a). It seems that with the inclusion of self-efficacy into the HBM, the model loses its original application to singly occurring health behaviours such as immunisations and screening exams and becomes more appropriate for longer term behaviour modification. Strecher and Rosenstock (1997) agree that the original focus of the model was on one-shot preventive actions classified as simple behaviours. Long term behaviour changes which involve lifestyle modification require the concept of self-efficacy as the person must feel confident in their ability to make and maintain change over time.

The HBM is a model which encourages behaviour change for the individual's benefit; rather than societal benefit. For example, its application to breast cancer screening or risk reduction practices in AIDS prevention are both applicable to an improvement of an individual's own health status. The improvement of an individual's health or the prevention of ill health is seen in the context of the individual and does not place the individual in a wider societal context. For example, if someone can be encouraged to change their behaviour to stop smoking on the basis that it will benefit those in the same household or working environment, then perhaps there would be an added incentive to stop. Is it not true that many pregnant women stop smoking because of the effect it may have on their unborn child?

One of the recommendations for further research suggests that where influencing the behaviour of larger groups is the target, interventions should occur at the societal level as well as at the individual level (Strecher and Rosenstock 1997). If the HBM could be applied to society as a whole, then health communication campaigns would have to convince society as a whole of their susceptibility to a disease, that the promoted action will alleviate or prevent the disease and then remove all possible barriers to action.

Within the HBM, beliefs and behaviour of the individual ultimately change the larger group (Streicher and Rosenstock 1997). As more people take up the action individually, the larger group should follow with similar actions. Within the context of LF treatment, it is unknown if the group impacts individual decisions more than the HBM-associated premise that individual beliefs and behaviour impact the larger group more.

### **Social Cognitive Theory and Self-Efficacy**

Social Cognitive Theory (SCT) is concerned with the interaction between individuals and their environments and how that affects health behaviour. The theory includes the concept of reciprocal determinism, which assumes that behaviour is dynamic and that the individual and the environment affect each other constantly. (Nutbeam and Harris 2004) This concept relates to MDA as the attitude or practices of the social environment (society) can affect – positively or negatively – a person's individual health behaviour. If the social environment encourages and supports the behaviour, then a person may perceive the behaviour to be more acceptable because surrounding society accepts it. This may be one factor in the continuum of the person's behaviour change.

There are several cognitive factors in SCT which affect and are affected by specific behaviours and environments: observational learning, behavioural capability, expectation and self-efficacy. Observational learning is described as a method to learn new complex behaviours. (Baranowski et al. 1997) It involves observations of others conducting a behaviour and the subsequent reinforcements that person receives for doing that behaviour. Consequently, the observer then makes a decision about their own health behaviour based on what they have observed. It is not particularly defined what a 'complex behaviour' is and I would argue that in lymphatic filariasis elimination, taking a drug cannot be considered a complex behaviour. However I would agree that observational learning does have some influence on treatment compliance when person A observes person B taking the treatment and this may reinforce person A's desire to comply with treatment.

Behavioural capability is another important concept of SCT which refers to a person's knowledge of the health behaviour and how to perform it. The behaviour must be clearly specified by health educators and involves an important distinction between what the behaviour is (knowledge) and how to perform it (skill). I would argue that this concept is too complicated for the simple pill-swallowing required by LF elimination programmes. It assumes that the behaviour requires mastery and skilled learning. In the context of LF elimination, or mass drug administrations on a wider scale, behavioural capability may refer more to knowledge of access to treatment and the ability to access it.

Outcome expectation refers to the events one expects to occur because of health behaviour. This implies repeated behaviour, for example smoking. People develop expectations about a situation where they will behave in a certain way and they will develop ways to handle that situation thereby reducing their anxiety. Baranowski and others (1997) illustrate this concept with an example of adolescent smoking. In a health education programme, adolescents should be taught how to handle pressure to smoke from their peers in order to delay onset of smoking. (Baranowski et al. 1997) Because outcome expectations assume repetitive behaviour, it is difficult to apply this concept to short term health interventions such as mass drug administrations.

The other closely related concept to outcome expectation is outcome expectancy which is the value a person places on an outcome. Generally, short term benefits are seen as better motivators for change than long term benefits which may be difficult to communicate and encourage. Again within the concept of ELF, short term benefits are not always directly perceived. Certainly, the immediate anti-helminth effect of Albendazole can be promoted as a short term benefit, however in terms of LF elimination; the benefit is inherently long term. Only with sufficient community compliance over the long term (4-6 years), will the MDA have any positive health benefit for the elimination of the disease.

Self-efficacy, another important concept in SCT, is defined as the confidence an individual feels about performing some activity (Baranowski et al. 1997). This

concept within the context of health promotion implies repetition of behaviour. By repeating an activity, a person increases his confidence; thereby increasing the probability that the new health behaviour will continue. With MDA, repeated behaviour is not required before a year. Participants are expected to comply with treatment once per year and practice is not required. As a result, the person does not necessarily develop confidence in their ability to perform that particular behaviour.

The constructs of the SCT are robust and as a result they cover many different aspects of the behaviour changes required in many health promotion programmes. It seems however that they refer to repetitive behaviours which are conducted over the long term. For example, jogging, quitting smoking and healthy eating are all mentioned in the literature to illustrate this concept. Because MDA in general and in particular within the GPELF, requires one-time behaviour (compliance with treatment) it is difficult to apply the Social Cognitive Theory with all of its elements. One of the criticisms of the theory is that it is too complex and as a result, when applied to health behaviour, there is a risk of oversimplification of the theory's complex constructs (Baranowski et al. 1997). It seems that this may be the case if this theory were applied to MDA for LF elimination. It may be more fitting to isolate certain concepts of the SCT to apply to the MDA, like reciprocal determinism and observational learning.

### **Theory of Reasoned Action and Theory of Planned Behaviour**

The theory of reasoned action suggests that the most important determinant of behaviour is a person's intention towards that behaviour. Direct determinants of behavioural intention include the person's attitude towards that behaviour and the subjective norms associated with the behaviour. Subjective norms relate to the person's beliefs about what other people think they should do. These are determined by normative beliefs (what other people think they should do). When combined with the Theory of Planned Behaviour, the concept of perceived behavioural control is added. This can be compared to self-efficacy and how much personal control a person has over their behaviour. The more control a

person feels about their own behaviour, the greater their intentions towards certain behaviours will become. (Montano et al. 1997)

In terms of the MDA, the theory of reasoned action may be an appropriate model to use in order to determine what factors influence behaviour to take the required treatment. The concepts of normative beliefs and subjective norms could be explored within the context of MDA to see if compliance with a wider benefit to the community is expected by the community (normative beliefs) and therefore a person complies as a result (subjective norms). The theory predicts that a person is most likely to adopt, maintain or change behaviour that will benefit their health, is socially accepted and that they feel a social pressure to do so.

One of the weaknesses of these two theories is that it assumes all other factors, including demographics and environment, do not independently contribute to the possibility of a person conducting a certain behaviour (Montano et al. 1997). In terms of GPELF, it is possible that environment may affect one's compliance with treatment. For example, in those villages where there is no clinical evidence of LF, people may be less interested in complying with treatment as this behaviour may seem unnecessary considering their perception of having a low risk for infection.

### **Community Organisation**

The theory of Community Organisation focuses more on health promotion initiatives which target communities and not specifically individuals. Communities can be defined as explained by Albert Hunter (1975) as “functional spatial units” (page 538) relating to their ability to meet basic sustenance needs, or as “units of patterned social interaction” or “cultural-symbolic units of collective identity” (Hunter 1975; Minkler and Wallerstein 1997). Regardless of the definition used, communities can simply be explained as how people organise themselves and operate as a group.

Theories of community organisation are dominated by Rothman's three models of practice: locality development, social planning and social action (Rothman and

Tropman 1987; Minkler and Wallerstein 1997; Nutbeam and Harris 2004). Locality development is primarily process oriented and emphasises community participation and methods that promote ownership of ideas in the community. Social planning is task oriented and professional where an epidemiological analysis of the health problems determines a planned programmatic response. Lastly, Rothman's model of social action is a combination of the two with a concern for processes which build community capacity where shift in the power relationships and resources will favour the disadvantaged. None of these three models are mutually exclusive.

Theories of community organisation and development continue to evolve in response to perceived limitations in Rothman's models. Rothman's three models are criticised for not representing the importance of capacity building within communities and fostering community empowerment (Nutbeam and Harris 2004). Newer models have suggested more about collaborative empowerment and community-building than the three first Rothman models (Labonte 1994; Minkler and Wallerstein 1997).

Empowerment becomes a key component of community organisation and community building despite the many different definitions and meanings it has been given within the context of social science (Minkler and Wallerstein 1997). Rissel (1994) argues that this ambiguity creates a stumbling block in the field of health promotion. He further divides the concept into two: community empowerment and psychological or individual empowerment. Through community organisation and community development, individuals become more empowered; subsequently translating into wider community empowerment. This process however, is not necessarily a linear one (Rissel 1994). In fact it could be argued that community empowerment and psychological empowerment are linked interchangeably, with each continuously influencing the other.

Rissel (1994) writes that psychological empowerment is enhanced by an individual's sense of community. Zimmerman and Rappaport (1988) explain psychological empowerment as a connection between personal competence,



desire, and willingness to take action in the public domain (Zimmerman and Rappaport 1988; Rissel 1994).

With this theory, the concepts of community and psychological empowerment are closely related, so the correlation exists that the more empowered the community is, the more empowered its individuals will be. The concept of empowerment is now recognised as one that comes from within the group, rather than one imposed upon the group (Rissel 1994).

The link between individual or psychological empowerment and community empowerment according to Minkler and Wallerstein (1997) is strengthened by the development of “critical consciousness” or as Paulo Freire calls it, “conscientization.” This consciousness comes from social analysis of conditions and people’s role in changing those conditions (Minkler and Wallerstein 1997). This concept implies awareness in the community in order for collective critical thinking and analysis to occur. Awareness may be nothing more than acceptance of circumstances and situations that are present, and the community may not be aware of their power to modify them. It would be difficult to assume that communities can have an increased consciousness without some catalyst, internal or external, and without some degree of communication between community members.

The concept of critical consciousness or conscientization can be applied to the ELF programme. In those communities where people with clinical manifestations of the disease live, villagers would be aware of the presence of the disease even though they may not know of their power to control the disease through compliance with the treatment provided. With conscientization, communities become aware of their own power to change the health situation of their village.

### **Trans theoretical model / Stages of change**

The trans theoretical model or stages of change model incorporates processes and principles from many different theories and models of health education (Prochaska et al. 1994; Prochaska et al. 1997). In essence it is a model based on

the premise that behaviour change is a process rather than an event (Nutbeam and Harris 2004). It describes the various stages that a person goes through when changing their behaviour.

The first stage is pre-contemplation when a person does not even consider changing their behaviour. Prochaska et al (1997) measure this period of time as within six months. It is possible that those in the pre-contemplation stage are unaware of the need to change their behaviour due to their lack of knowledge. It is also possible that they have tried in the past to change but were unsuccessful and, as a result are discouraged from any further attempt to change (Prochaska et al. 1997).

The second stage is contemplation. Here the person considers making a change to a specific behaviour. The period is defined to within the next six months. During this time, the person weighs the benefits and costs of changing his behaviour. Prochaska et al (1997) write that people can stay in this period for some time weighing the pros and cons, characterising this period as chronic contemplation or behavioural procrastination.

The third stage is determination (Nutbeam and Harris 2004) or preparation. The person intends to make a serious commitment to change at this stage, and usually within the next month. At this point, they usually have taken some initial steps towards change like buying a book or joining a class. (Prochaska et al. 1997)

The fourth stage is action, when the behaviour change actually occurs. Again Prochaska et al. (1997) quantify this period as one where behaviour has been modified within the last six months. Total behaviour change is required in this model, not simply modifications towards change. In order to be included in the action stage as stopping smoking, only total abstinence will be counted in the trans theoretical model – reduction is not acceptable. (Prochaska et al. 1997)

The fifth stage is maintenance which is where the person sustains the change and attempts to prevent relapse into unhealthy behaviour again. In terms of time,

Prochaska et al (1997) estimate that this period last from six months to five years. During this time, the person will be increasingly confident that they will not relapse and can maintain their new behaviour.

The final stage is termination and does not apply to all behaviours. In terms of addictive behaviours like smoking or alcoholism, this is the stage where the person is 100% confident that they will not relapse into the behaviour again (self-efficacy) and is non-dependent on their mood or situation. (Prochaska et al. 1997)

Since the trans-theoretical model relates more to long term behaviour change, it is not applicable for use in LF elimination programmes. The theory is best applied to lifestyle changes such as condom use, stopping smoking, reducing calorie intake, getting a regular mammography – actions which require the six stages outlined in the model. Within the context of MDA, a person does not have six months to think about a change, six months to prepare for it and then five years to maintain the change. The length of time between the steps is significantly reduced in any mass intervention. The person may become informed about the upcoming mass health intervention and then depending on their eligibility, they may be expected to partake of the intervention.

The model incorporates ideas from Janis and Mann's decision-making or conflict model. The model suggests that a person asks several questions before making a decision concerning his health. He weighs the costs and benefits of the decision in the following terms: (1) gains or losses to self; (2) gains or losses for significant others; (3) approval or disapproval from significant others; (4) self-approval or disapproval. (Prochaska et al. 1994) From this model, the trans theoretical model takes only two factors into account, the pros and cons of the behaviour within each of the different stages of change (Prochaska et al. 1994). The concept in its original format from Janis and Mann is more applicable to LF elimination than the revised version included in the model. Community or social pressure enters into the decision-making process as the person weighs the opinions of others. He/she will also consider the gains or losses (costs or benefits) to himself/herself and to others that will occur as a result of his/her decision.

## **3.2. RATIONALE FOR THE USE OF A DIFFERENT THEORETICAL PERSPECTIVE**

As the results from the preliminary KAPB showed, knowledge and risk perception do not seem to be pre-cursors for compliance and the emergence of new themes which are more group-related than individual-related suggests that there are other influencing factors at work which fall outside of the conventional health promotion theories.

Furthermore, although mass drug administration (MDA) offers considerable promise in the elimination and eradication of infectious diseases, high compliance rates (participation of all eligible members in endemic populations for 4-6 years) are necessary so that the intervention is effective (Ottesen et al. 1997; Gyapong et al. 2001). Unlike other strategies, which focus on solely protecting the individual, MDA requires a willingness to participate for the benefit of the whole community. MDA differs fundamentally from individual treatment in that it applies to large numbers of people who may perceive themselves to be well, and yet may temporarily feel ill as a result of the intervention due to adverse reactions. The benefit of the community's compliance is largely group-related (i.e. it benefits society as a whole to reduce the incidence of the disease) although there are individual benefits which may or may not be perceived. In LF elimination, individual testing before treatment is not recommended as it has been shown to be time consuming, expensive and inconvenient (night blood) at a mass community level. As a result, people who take the treatment may have mf in their blood and may not know it. This person may benefit personally from the treatment; however it is unlikely he will ever know.

The role of individual motivations to practice risk reduction behaviours because they are members of a larger group, has as yet been little investigated. Several of the current health behaviour models touch upon certain related themes, like reciprocal determinism in the Social Cognitive Theory, subjective norms in the Theory of Reasoned Action and Planned Behaviour and in the critical

consciousness of the community organisation models. However, these models tend to maintain their focus on motivating the individual to change his or her behaviour because of a direct benefit to himself/herself as an individual. Additionally these models deal primarily with lifestyle changes (smoking, fat reduction in the diet, exercise) and do not elaborate on models which involve immediate behaviours with results that may only be perceived in the long term. Most models also assume a person's knowledge and perception of susceptibility to risk of infection.

Furthermore, evidence of the effectiveness of health education in individual behaviour change has, on the whole, been disappointing (Loevinsohn 1990; Cave and Curtis 1999). A more intensive focus on interventions which aim to influence group norms governing health behaviour, and the social context in which that takes place, is necessary in current preventive medicine. In light of a recent drive by the international health community to eradicate and eliminate certain infectious diseases worldwide, now more than ever, a re-visitation of the theoretical basis for mass interventions is needed to improve the theoretical underpinnings of current health promotion practice.

In an effort to search for a new theoretical perspective to address the challenges to compliance, I was led to a theory in behavioural economics which considers the individual's acceptance to a public good offered to the entire community. His/her uptake of that good is dependent on many factors – among them his/her willingness to cooperate with his/her fellow community members in order to achieve the benefit of this public good. His/her temptation to refuse the public good but enjoy the benefits of the rest of the community's acceptance is also described. This theory, called social dilemmas, will be discussed in the following section. Although it does not address all of the factors at work in MDA for LF elimination, it encompasses many of the influences which were expressed in the KAPB and provides insights onto how to proceed with the more in depth investigation into motivations which I did in the second half of my field work in 2005.

### **3.3. CONCEPTUAL FRAMEWORK GUIDING THE RESEARCH**

#### **3.3.1. SOCIAL DILEMMAS**

The nature of LF elimination requires that there is constant cooperation amongst members of the community or group in order for everyone to benefit from the MDA. An individual who is called to participate in the MDA will weigh the various risks and benefits of complying with treatment. This process will involve both health related and non-health related issues. The theory that seems to me to best describe this individual tension is that of the social dilemma. Dawes defines social dilemmas as situations where “each individual always receives a higher payoff for defecting than for cooperating, but all [individuals] are better off if all cooperate than if all defect” (page 111) (Dawes and Messick 2000) Assuming that people seek to minimise their own effort, with all public goods, there is a temptation to enjoy the good without contributing to it in any way. This is possible if not all members of society respond to the public good in the same way, i.e. to take but not contribute. In a social dilemma, an individual must weigh the costs and benefits of being a “free-rider” meaning that they do not participate in the collective action, but would still benefit from the actions of their community. Of course, if there are too many free riders, then no one benefits from the action.

The LF elimination programme is in essence, a social dilemma – ensuring collective action or cooperation (i.e. swallowing the pills for 4-6 years) in order to reach a common output, in this case, the elimination of a disease for the whole community. The higher payoff for defecting individuals is no personal time lost and no risk of adverse reactions post-treatment<sup>7</sup>. If all persons cooperate however, LF will be eliminated and all will benefit.

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<sup>7</sup> We assume of course, that these defecting individuals were not carriers of the infection at the time of the MDA. There is of course a personal benefit to curing an existing infection; but due to the lack of diagnosis prior to treatment, individuals who show no outward signs of disease, would most likely consider themselves to be LF-free.

Game theory is widely used in the social sciences to explain how individuals are likely to act when the outcomes of their actions depend on what others do. The prisoner's dilemma is a classic game where two prisoners are faced with the choice of giving evidence against each other thereby reducing their own sentences; however if both remain silent and cooperate, then they cannot be convicted due to lack of evidence and as a result, both will receive lighter sentences. Each would be individually better off if they defect and give evidence whilst the other cooperates, but both are better off if they cooperate together. (Lichbach 1996; Ridley 1997) Although the prisoner's dilemma is the most frequently used explanation for the tension between cooperation and defection, it involves only two actors. With a social dilemma, there are multiple actors. According to Kollock (1998), there are two possible outcomes for multiple actor social dilemmas: the social fence or the social trap. A social fence is where an individual is faced with an immediate cost that will generate a benefit to all, whereby a social trap is where the individual is tempted by the immediate benefit which produces a cost borne by all and if the individual gives in to this temptation, there is a less favourable result for all. Provision of public goods is a social fence whilst the tragedy of the commons is a social trap.<sup>8</sup> Not cooperating with a mass LF elimination campaign is a social trap because individuals who refuse gain an immediate benefit of not suffering potential pain, but thereby reduce the probability that LF will be eliminated from their community.

LF treatment can be considered a public good, which by definition means that it can be consumed by every member of a group regardless of his or her contribution to the good and where access to the good cannot be effectively restricted (Fehr and Fischbacher 2003). Individuals are asked to cooperate by contributing to the production of this public good. In order for LF elimination to succeed, sustained cooperation of individuals to accept this public good must occur in all endemic communities. The benefit to the individuals may not always

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<sup>8</sup> The tragedy of commons can be explained using the example of an individual catching every day the largest fish in the pond and noticing that after some time, there are no large fish left in the pond. Unknown to him, all the other fishermen have been doing the same thing, thinking that their individual actions will not affect the group in any way. Hardin, G. (1968). "The Tragedy of the Commons." *Science* 162: 1243-1248.

be clear in the beginning. For example, why would individuals cooperate voluntarily in MDA; particularly when they may suffer adverse reactions from the treatment and they feel no risk? What possible forces are at work within the community which might explain their reasons for compliance? In order to understand these reasons, we must understand how the social environment an individual lives in might affect his/her reasons for compliance and thus the individual's cooperation with the rest of the community.

From the evidence seen from the KAPB survey, I believe that there are several explanations as to why an individual would cooperate with his larger community: strong reciprocity or altruistic sanctioning, kinship, reputation formation or indirect reciprocity, the possibility for repeated interactions, and self-interest. These themes are not independent of each other and co-exist in real world situations. I will explain each of the concepts individually and how they may provide a solution to the social dilemma of mass drug administration for LF. (They are dealt with below, in no particular hierarchy of order.)

I will use Smith's (2003) definition of cooperation: "whenever two or more individuals must interact or coordinate their actions to achieve some end" (i.e. collective action) for mutual benefit" (page 402) (Smith 2003).

### **Self-interest**

An individual may consider only himself/herself when agreeing to comply with treatment. If there is a benefit for others, that is an added bonus to his/her action. Self-interest in relation to health may also link to wider values, such as success and happiness. If an individual is healthy, then he/she will have a greater economic gain or participate better in school. There may be other external factors at work; however it is also possible that he/she simply wants to be healthy. Self-interest with regards to compliance with LF treatment assumes that the individual is aware of the drug's benefits to cure disease. For those infected individuals, self-interest may be the overwhelming motivation to comply with treatment.



It should be noted, however that many economists and behavioural scientists acknowledge that a strictly self-interested model explaining a person's actions is limited (Judd et al. 2001); so it is unlikely that within LF treatment, people comply only out of self-interest.

### **Group Membership**

Many of reasons given for compliance which I investigate further in the in depth interviews are framed by the individuals' placement in a community or a group: fear of sanctions, respect of government authority, protection of family members, friends and neighbours, desire to be socially accepted in their community, etc. Within the context of LF elimination, it is possible that individuals are influenced to comply because of various reasons associated with the group that they belong to.

For the purposes of this research, I will use the sociological definition of a group: "social groups are collectivities of individuals who interact and form social relationships" (page 108) (Abercrombie et al. 1988). It is understood that people in groups interact repeatedly, thus enhancing their membership to the group.

Within groups, there are varying degrees of relatedness and sociality between members (Gintis 2000). Within the context of this research, it will be important to understand how groups are defined by the people themselves. Are groups in Alor defined at the household level or by connection with direct kin in the village? Are they defined by geographical (neighbourhood, village, sub-district, district), religious or administrative boundaries? One person will undoubtedly belong to several groups at once; but which of these groups has the most influence on that individual's participation?

The duration of the group is determined by the nature of the interaction between individuals. (Sober and Wilson 1998) Duration also implies the degree to which there will be future interaction between members of the group.

A group's size is associated with the level of cooperation present. Sober and Wilson (1998) write that "the large anonymous societies of today are recent inventions; human evolution took place in small groups whose members had extensive opportunities to observe and talk about each other. Information about a single antisocial act can quickly spread through a social network and spoil a person's reputation, with grave consequences for future social interactions" (page 141-2). The size and duration of the group would seem likely to have an important influence on individual motivation.

Regardless of size, constitution or duration of the group, there are several factors which bind a group together and provide the right environment for cooperative behaviour. In Tuomela et al (2003), the authors extensively define these factors and how they influence individual and group behaviour. Theirs is the first definitive work on group acting individuals. Because groups are formed or because people identify themselves with a group however does not, by that fact alone, mean that cooperation is ensured (Dawes and Messick 2000).

At a foundation level, groups are held together by their common ethos (beliefs, standards, goals, or aims) and their "realm of concern" (page 11) (Tuomela and Tuomela 2003). Individuals agree to this ethos becoming participating members in the group.<sup>9</sup> Within the group, most actions which follow are to promote or sustain this group ethos. A group's realm of concern is its acceptance of certain topics to be concerned with; whether economic, political or in some cases, genetic. (Tuomela and Tuomela 2003)

A group's ethos is largely reflected in the belief and observance of social norms which are sustained by members' emotions (guilt, anger or embarrassment) when confronted with the possibility of not upholding them (Elster 1989; Bowles and Gintis 2003). Some examples of social norms include: consumption norms which regulate dress, table manners, etc.; norms against behaviour which is "contrary to nature" (page 100, Elster 1989) like cannibalism or incest; norms of reciprocity

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<sup>9</sup> Of course there are persons, like criminals and deviants, who do not accept the ethos of the group, as they perceive that working outside the group norms has more benefits for them. It is likely that these individuals will suffer punishment for their deviance.

which assume that favours will be returned; retribution norms where those who cause harm are punished; and norms of cooperation, including fairness norms and justice. (Elster 1989) These social norms impose expectations on group members for participation, action, and acceptance. Within the context of this research, we may expect coverage rates to be higher if compliance is communicated as a social norm.

The literature further describes several themes which determine a group's cohesiveness and ability to act as a group namely collective acceptance, mutual belief/mutually known and social commitment. Collective acceptance refers to holding what Tuomela and Tuomela (2003) call a 'we-attitude', or belief in something with the confidence that others in the group also believe it. Mutual belief occurs when individuals in a group believe that others in their group will perform a normative action as they themselves also plan to do. Mutually known actions occur when individuals make public their intentions to perform a certain action and that they are committed to the ethos of the group. With this public display, individuals can sanction other group members for not carrying out the action they said they would do. (Tuomela and Tuomela 2003) Finally, social commitment is defined as commitment to oneself and to the other participants of the group in the jointly intended action. Each group member expects the other members of his group to do the action, just as he has agreed to do the action. It is public and therefore a defector can be openly criticised for his refusal to join the action. (Tuomela and Tuomela 2003) Within groups, there is a higher expectation that actions will be reciprocated; therefore it is difficult to distinguish between what appears to be an altruistic action (action for the benefit of the group) and an individual's strategy for long term survival within the group (Kollock 1998).

(These themes (namely subjective norms) are touched on within the theory of reasoned action and planned behaviour; however as a solution to social dilemmas, the concept of group membership is much richer in providing possible scenarios for the creation and maintenance of norms.)

The next three sections (repeated interactions, strong reciprocity and reputation formation) consider different mechanisms for promoting cooperation within a group.

### **Repeated interactions**

Individuals who are in ongoing relationships are more likely to cooperate. In Prisoner's Dilemma games where individuals do not know each other, the dominating outcome will be self-interest or defection rather than cooperation (Kollock 1998). Specifically, Axelrod (1984) explained that there needs to be an ongoing relationship, individual recognition or knowledge about an individual's past behaviour in order for cooperation to emerge as a possibility. (Axelrod 1984)

The chance for repeated interactions with people one knows or even trusts is better in smaller communities or kin groups. The larger the group, the less chance there is that individuals may meet each other or rely on each other's behaviour. Of course, random interaction is possible in urban groups, but it may be less trustworthy than the interaction which occurs in smaller groups. In fact, studies have shown that as groups enlarge, cooperation declines (Kollock 1998). Repeated interactions provide an environment for the maximisation of strong reciprocity.

### **Strong reciprocity**

I have mentioned briefly the possibility of sanctions or punishment within groups as a possible solution to social dilemmas. Sanctions are a way to ensure that group members act for the ethos of the group. When groups consist of unrelated individuals, cooperation is more difficult to ensure since the element of helping your kin (kin altruism (Hamilton 1964)), to perpetuate your own genes will not exist (Dawkins 1989). In these situations, strong reciprocity offers an answer as to why people would want to cooperate with non-related individuals (non-kin) in situations where they may not receive back the same benefit they are giving to others (reciprocal altruism (Trivers 1971)). Strong reciprocity is the "predisposition to cooperate with others and to punish those who violate the norms of cooperation, at personal cost, even when it is implausible to expect that

these costs will be repaid” (page 153) (Gintis et al. 2003). Strong reciprocity is present when cooperation occurs in non-related groups where reciprocal altruism and self-interest do not justify cooperative behaviour (Gintis 2000).

Within a social dilemma, there may be sanctions or punishment for those who are identified as free-riders, non-participants or defectors. Fehr et al. (2002) describe the propensity of humans to cheat in social or economic situations where all of the contracts’ conditions are not enforceable. Note that participation in LF treatment is not enforced by contractual agreements between health officials and individuals, and individuals are asked to voluntarily comply with treatment, making cheating or free-riding easier.

In experimental games such as the ultimatum game or the public goods game, researchers have shown that where punishment is allowed, cooperation continues, even under conditions of anonymity between respondents, which eliminates an individual’s ability to build one’s social reputation through compliance (Gintis et al. 2003). When punishment is removed however, cooperation deteriorates. Fehr and Gächter (2002) found in their experiments that the strength of punishment is more or less the same regardless of the participants’ knowing the other individual. The threat of punishment is equally as effective as the punishment itself in promoting cooperation. The authors suggest that strong reciprocity is more manifest in those groups which are more coherent and permanent. (Fehr and Gächter 2002)

One of the criteria for defining strong reciprocity is that the punishment of a defector must occur at a personal cost, even when the cost may not be repaid (Gintis et al. 2003). Thus, it appears that this punishment is altruistic or an act of fairness-based altruism, (Fehr and Rockenbach 2003) since the punisher himself will pay for the punishment, whilst the rest of the group will benefit from it since the number of defectors will be reduced (Fehr and Gächter 2002). There is also an aspect of the social dilemma in strong reciprocity: a punisher may imagine that there are other members in the group who might incur this cost by punishing, so the punisher may ‘defect’ and still enjoy the benefits of improved group

solidarity since someone else did the punishing. Why then would the punisher be interested in punishing at a cost to himself or herself? Fehr and Gächter (2002) suggest that negative emotions may provide an explanation. Free riding creates negative emotions, namely anger, within the group towards that person and that emotion motivates punishment.

Strong reciprocity is one strategy to encourage cooperation between non-related individuals. If we consider that rural villages contain mainly groups of related individuals, then it will be difficult to tease out the influence of strong reciprocity where society is organised according to kinship. Dawkins writes about viscosity, which is defined as the tendency for individuals to live close to the place where they were born throughout their lives. As such, there are places where individuals in a small clustered area are related to a certain degree, thereby forming genetic clusters. (Dawkins 1989)

Drawing on the concept of viscosity, I would suggest that there may be stronger elements of kinship within small communities than in the larger urban areas. That is, the average degree of genetic relatedness between two random individuals in an urban area should be lower than in rural areas.

### **Reputation formation**

In groups, individuals who cooperate may be known for their cooperation and may receive more favourable treatment by other group members as a result (indirect reciprocity (Alexander 1987)). Essentially, co-operators are paid for their cooperation with the image of being a “valuable community member” (page 573) (Nowak and Sigmund 1998). In social systems, there is a continual assessment of group members and their reputation and status within the group (Alexander 1987). People who cooperate have a good reputation and others within their group will be more apt to cooperate with them because of this positive image or reputation (Nowak and Sigmund 1998). This reputation is made known to others within the group by direct observation of the person’s behaviour or by information from other group members (Nowak and Sigmund 1998). Within the context of the costly signalling theory, these observable acts are

signals, often made at a cost to the individual, which reveal information about the individual's essential qualities (Smith 1971). Individuals who demonstrate that they are good or cooperative people are more likely to have a positive reputation which will make them more likely to receive benefits from others in their community at a later date. Similarly, punishing a defector can be a signal of one's commitment to the group and may also enhance reputation (Gintis et al. 2001). Boyd and Richerson (1989) found that indirect reciprocity is likely only in small groups since it is easier to witness an individual's cooperative act and monitor him over time than in larger, more impersonal groups (Smith 1971; Boyd and Richerson 1992).

Within LF elimination, complying with treatment can be a public action, particularly when individuals are targeted to take the treatment after a church service or a village meeting. People who do not comply will be observed by their fellow community members and their reputation may suffer. There are policy implications for MDA when considering reputation formation. If it is found to have an impact, then it would be recommended to make compliance with MDA as public as possible.

## **CHAPTER 4: METHODOLOGY**

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### **4.1. INTRODUCTION**

As noted above, few current studies describe in depth reasons for compliance or non-compliance in individuals, particularly after several years of MDA. Repeated calls have been made for more investigation into this complex area; since the success of the MDA in eliminating LF depends wholly on the participation and compliance of endemic communities. Without a solid understanding of the specific factors which influence compliance, public health planners may “miss the mark” in convincing individuals and their larger communities to maintain their commitment to the full course of the MDA.

This research was conducted in Alor District in 2004 – 2005. Alor District was chosen because of my own extensive experience working in LF elimination there (see Chapter 2). Furthermore, Alor had experienced a series of successful MDA campaigns where recorded reported compliance had been high (e.g. above the margin required for elimination) (see Table 1). Because this research aims to study the motivations people report for their compliance, Alor District provides a large enough complying population for this research. As I will focus on the exploration of social dilemmas and associated group themes within the context of MDA and LF elimination, the group effect on compliance will be easier to observe in larger complying groups, like we have in Alor. However as this seems to be a primarily complying population, what about the non-compliers? I will discuss in the upcoming chapter (section 4.5.) the sampling strategy I use for the in-depth interviews which focuses on an equal spread of respondents between compliers and non-compliers. Because non-compliers are a smaller group in Alor, it is important to seek them out equally to understand better their motivations and to identify if they are indeed representative of other non-compliers in populations where greater proportions are non-compliant.



The preliminary KAPB survey was conducted after the 3<sup>rd</sup> year of MDA in Alor District in November 2004 and qualitative research following the 4<sup>th</sup> year of MDA in November 2005.

## **4.2. KAPB SURVEY RESULTS AND RATIONALE FOR THE USE OF IN DEPTH INTERVIEWS**

As seen in Chapter 2, a preliminary quantitative survey in which I was involved had investigated the knowledge, attitudes, practices and behaviour (KAPB) of Alorese people in relation to LF and its treatment. A quantitative survey typically requires short, succinct answers and provides few opportunities for discursive answers, even though some open ended questions may be included. The preliminary KAPB survey, despite its deficiencies in revealing complex factors relating to the decision to comply or not to comply, provided some insights into fruitful areas of further investigation and helped to guide the formulation of the topic guide for the in depth interviews.

Green and Thorogood (2004) suggest that qualitative studies can add depth to surveys and can explore associations between variables which quantitative surveys uncover but cannot explain. A number of themes were identified in the quantitative research which warranted further exploration in the qualitative research. These themes were raised briefly in the open-ended questions in the survey but needed further investigation in order to understand the mechanisms by which they may be acting. For example, the KAPB survey findings suggested that knowing little about LF could still be correlated with compliance with treatment (see table 2). Carrying out in depth interviews provided the opportunity to explore this apparent anomaly. (Green and Thorogood 2004)

As noted above, one of the primary research aims was to explore people's perceptions and understanding of LF and its treatment, and the causes they give for their action in relation to compliance with MDA for LF. The use of in depth interviews provided an opportunity for the researcher to explore directly certain topics during the course of the interview, leading to a better understanding of the respondent's perception of LF, its treatment, the drug delivery process and

potential influences on their behaviour. Furthermore, in depth interviews allowed the respondent the freedom to discuss what he or she wanted in respect to the subject of LF, the MDA and compliance. To this end, in depth interviews were conducted with 43 individuals throughout Alor Island in November 2005.

Within the context of this research, the in depth interview was determined to be the most appropriate method to explore the themes which had arisen in earlier field work and in the KAPB study. In depth interviews are often used in qualitative research as they provide an opportunity for the researcher to engage directly with the respondent to refine a prior hypothesis, to explore meanings and perceptions and to generate hypotheses (Dicco-Bloom and Crabtree 2006). In depth interviews generate information about the understandings of a particular group of people with regards to a specific research topic (Peck and Secker 1999; Dicco-Bloom and Crabtree 2006) in a manner that represents the respondents' "own stories in their own words" (page 378) (Bowling 2001).

However, despite the value of in depth interviews in identifying certain phenomena and in providing rich descriptions of those phenomena within a population, as a researcher, I must also be aware of the pitfalls surrounding this type of research method and attempt to avoid them. One of the frequent criticisms of in depth interviews is the problem of what Silverman (2000) calls 'anecdotalism' whereby the researcher only presents a few examples explaining a certain phenomenon without making any attempt to analyse and present less clear results. This criticism is directly related to the validity of some qualitative research; that is, the validity of the findings can be questioned when the researcher does not present contrary cases for his or her reader to consider. (Silverman 2000) In order to increase the validity of my research, I have included for consideration deviant cases or outliers which arose from the data when discussing larger concepts or themes. By doing this, I am also able to show the variation of phenomena across the interview population as well as provide insights into why deviant cases exist.

There is also the criticism that the qualitative researcher may find it difficult to think theoretically when analysing the interview since he or she has interacted directly with respondents and may not possess “sufficient distance” (page 110) from them to interpret the findings beyond an oversimplified explanation which amounts to common-sense (Silverman 1998). As Peck and Stecker write (1999) “the researcher has to minimize the intrusion of his or her own preconceptions by setting aside prior assumptions...” (page 555). One way to avoid over-identification and assumptions with research respondents is to consider historical, cultural, political and contextual sensitivity when building theory (Silverman 1998). In order to do this, I have added in the beginning of most sections in the results (Chapter 5), segments called ‘scene setting’ which provide for the reader an overview of the historical, political and cultural issues in Alor and in Indonesia which are necessary to understand in order to frame the results. As Silverman writes (1998) contextual sensitivity is more difficult to identify (than historical, political and cultural) and depends on the understanding that participants develop their own contexts for what they do and that these may hold different meanings depending on the situation. In order to include contextual sensitivity in my results, I report both real-life accounts of compliance as well as hypothetical accounts, based on the use of drawings (see section 4.6.1.). By seeing how respondents describe the same situation in different contexts, we are able to see more clearly how context alters their interpretation and understanding of certain phenomena.

Finally, a further limitation of in depth interviews is the generalisability of results – is what has been observed in Alor in 43 in depth interviews generalisable to other people living on Alor, for example? One of the ways to address this issue is to ensure that there is enough representativeness in the respondents chosen for in depth interviews either by using theoretical sampling or random sampling (Silverman 1998). In the selection of respondents, as seen in section 4.5. below, I attempted to use both theoretical and random sampling so that the respondent population represents a cross-section of people living in Alor in terms of:

different population densities, different endemicity for LF and different choices with regards to compliance with LF treatment.

### **4.3. ETHICAL ASPECTS**

Ethical approval for this research was granted by the London School of Hygiene and Tropical Medicine and by the National Institute for Health Research Development (NIHRD) in the Department of Health, Indonesia. A participant information sheet and informed consent form were approved for use by both ethical committees. According to NIHRD guidelines, I was required to provide each responder with a small towel and bar of soap as a token of appreciation for their participation at the end of the in depth interview. All interviews were to remain anonymous and any recorded data would be kept by myself for safe-keeping.

I was able to adhere to all of the assurances I gave with regards to the ethics committees at the London School of Hygiene and Tropical Medicine and the NIHRD; with the exception that one CD with data from a selection of interviews was destroyed by a transcriber I employed in the UK to assist me. I attempted on numerous occasions to retrieve the CD from him. In our last correspondence (in 2007) regarding this CD, he informed me that he had destroyed it himself whilst in the UK. I must take his word upon this fact; and would add that the taped interviews were anonymised anyway and no names would have been recorded, so I do not believe that the identities of anyone I interviewed were compromised.

### **4.4. USE OF KEY INFORMANTS**

Several people in Alor and in Kupang assisted me with interpretation of cultural and language issues as they arose in the interviews. They included a German Catholic nun who had worked as a nurse for 35 years in NTT province; my research assistant – a PhD candidate in linguistics (Sebastian Fernandez); a staff member of a local NGO (Mr. Daniel Obetnego); an interpreter for German government organisation (Mrs. Heny Nggadas); and a linguist (Dr. František Kratochvíl) from the University of Leiden whose studies of the Abui language in

Alor District coincided with my period of field work in 2005. I refer to these people and their insights throughout the dissertation.

#### 4.5. SAMPLING STRATEGY

A purposive sampling strategy was used for the in depth interviews. The matrix (table 3) meets the need for what Ritchie et al (2003) call symbolic representation and diversity within the sample. That is, the sample represents relevant components of the research question, in this case, compliant or non-compliant behaviour, whilst diversity within the sample provides a greater range of observed phenomena; optimising opportunities for examining the relationship between certain variables. (Ritchie et al. 2003) Furthermore, this fulfils Silverman's (1998) recommendations to ensure representativeness across the sample.

The intention was to have equal numbers of people in each quadrant, and to achieve a total sample of some 40 interviews. Ten people in each quadrant provided 20 people in any given category for comparison with the other category of interest (compliers vs. non compliers or high prevalence vs. low prevalence). I also attempted to reach a gender balance in the sample. Anyone over the age of 15 years was eligible for interviewing, this lower age limit being consistent with the sample in the previous KAPB survey.

**Table 3 Sampling matrix**

	Complier with treatment	Non-complier with treatment
High Prevalence area		
Low/No Prevalence area		

To account for possible differences in compliance between more populated areas and the rural areas in the sample size, the sample included people from areas of different population density on Alor (from district capital to remote village). The most urban area of Alor District, its district capital of Kalabahi, is considered to

be rural and remote compared to Jakarta or even to the provincial capital of Kupang (population 250,000), yet Kalabahi can nevertheless be considered 'urban' when compared to the most rural and remote villages in Alor which can take hours to reach by foot, boat or car, have no electricity and where health centres remain unoccupied due to their remoteness. Kalabahi has a more mobile and educated population and people are less likely to live in large kin groups as they would in a rural village.

Several other considerations influenced the choice of villages for the interviews. First, I had worked in Alor repeatedly in 2002-3 and needed to conduct interviews in villages in which I had not worked in order to reduce bias. Secondly, to reduce recall bias, I wanted to interview people who had already taken their fourth round of LF treatment in 2005, and not all villages in Alor had carried out the MDA when we started our research in November. Thirdly, I needed to identify areas it would be feasible to reach within the field work period. Some areas in Alor take days to reach, particularly when the rains begin and the seas are rough. Because two types of filariasis are present on Alor, it was also preferable to include people from areas with *B. timori* and from those with *W. bancrofti*.

## **4.6. DATA COLLECTION**

### **4.6.1. THE RESEARCH TOOL**

An unscheduled, semi-structured topic guide was designed to guide the interview to ensure that all the main themes were included in the discussion. It was developed in the field (Appendices A.3 and A.4.) in Alor and translated by the research assistant. Because at the onset of the research, two researchers were involved in the interviews (myself and the research assistant), the design needed to be somewhat detailed, with reminders for prompts and suggestions for wording. Main topics included perception of the cause and transmission of LF; local terminology; perceptions of personal susceptibility and prevalence in the community; the drug delivery process; reasons for compliance; perceptions of

compliance patterns among others; and the perceived costs and benefits of the treatment.

The interview began with a simple introductory question about health in the village – specifically “what are the health problems in your village” or “what do people mostly get sick from in this village?” – aimed at starting discussion in a non-threatening way before more specific subsequent questions about LF followed. This said, one of the first questions in the interview asked about the respondent’s compliance since, because of the quota sampling design, we needed to determine at the beginning of the interview whether the individual was a complier or not, so that we could move onto another house if needed. Additionally, it was important to ask about an individual’s behaviour before we asked them their attitude towards that behaviour.

We asked respondents to tell us about the day of the MDA. If respondents were reticent, shy or had little to offer in this respect, we prompted with a series of pictures representing the different forms the distribution could take: that is, central point distribution, health service distribution, house to house distribution and directly observed treatment. (Appendix A.5)

The next section of the interview involved a discussion of two pictures (Appendix A.6) representing hypothetical situations of compliance and non-compliance. This is discussed in more detail in the next section “Use of Pictorial Prompts.”

Towards the end of the interview, respondents were asked to rank order a series of five statements in terms of importance to them as individuals. The statements were as follows: “Take your pills so you don’t get filariasis”, “Take your pills so your children won’t get filariasis”, “Take your pills so our community doesn’t get filariasis”, “Take the pills so Alor doesn’t get filariasis” and “Take the pills so Indonesia doesn’t get filariasis.”

### **Use of pictorial prompts**

In the preliminary quantitative KAPB survey preceding this qualitative study, responses to some open-ended questions about causes for compliance had been brief and cursory. Anxious to avoid a similar kind of response in the depth interviews, I discussed possible approaches with colleagues in the Sexual Health Unit at LSHTM and I also investigated different marketing styles of interviews (Zaltman 2003). The use of pictures appeared to be a promising way of encouraging people to talk more freely. I therefore commissioned a local artist in Kupang (Jakob Ndolu), who had worked with me on previous health promotion projects in eastern Indonesia to draw a series of pictures (Appendix A.5 and A.6.). I described for him what the pictures should look like to best represent Alor, the MDA as well as the hypothetical situation relating to compliance and non-compliance.

Following detailed discussion about the respondent's own behaviour and beliefs during the interview, we used the pictures to orient the discussion to a hypothetical situation on which respondents were invited to comment. We presented them with two simple illustrated black and white pictures representing compliance and non-compliance with MDA for comment. The two images were almost the same (see Appendix A.6.) showing two children playing together in the forefront of the picture, a man standing in the door in the background watching the scene, and a woman seated at a table with a pitcher of water, the tablets and a glass. One picture shows her taking the pill, the second shows her refusing to do so, ignoring the glass and tablets in front of her. Respondents were asked to describe what they thought was happening and why; who the people were and what their relationship was to one another. Finally they were asked to make a judgment on the two kinds of women – the non-complier and the complier – in terms of the future outcome of their behaviour (often leading to a statement on their moral worth), and to describe which woman they would prefer as their neighbour and why? The strategy of using hypothetical images or stories for discussion is called a 'projective technique' and is designed to elicit emotions and beliefs about a situation which may not be at the conscious level of the respondent (Arthur and Nazroo 2003). By commenting on a situation outside of



themselves, respondents were able to reply safely and with greater ease using their own emotions and judgments.

### **Collecting the data**

I was accompanied by an Indonesian assistant who was initially responsible for helping me conduct the interviews. He was a linguist from a nearby district, who had experience in field research and who was currently working on a PhD at an Indonesian university. I was recommended to include a local Indonesian research assistant in my data collection by my upgrading committee in March 2005. They felt that I would benefit from the language assistance during the interviews. I involved the research assistant in the development of the topic guide and its pre-testing in order to improve his familiarity with the project, the style of depth interviews and his understanding of the research questions and aims. Such a strategy is recommended in order to maximise the assistant's understanding of the research and the methods of data collection (Green and Thorogood 2004). Furthermore, he benefited from direct input from my supervisor, Professor Kaye Wellings, who came with me to the field to observe and supervise the beginning of the data collection process.

After piloting the topic guide with two individuals in a mountainous village (Apui), it became evident that despite his early involvement, the research assistant did not fully grasp the Alorese culture and the depth interview techniques. His pilot interviews demonstrated that he asked questions which often left the respondent with only a yes/no answer rather than provoking more discursive answers. In addition, he left little time during the interview for the elaboration of any comments by the respondent. I quickly saw that the rich detail I was anticipating from the interviews would in fact not come through with his interview style and technique. As a result, I took over the role of principal interviewer, as I am able to speak Bahasa Indonesia and am accustomed to the eastern Indonesian manner of speaking in Alor; and he provided linguistic advice and translation as it was needed during the course of the interviews.

On entering a village, we went first to the health centre to inquire about where and when the MDA had taken place. We asked about areas where there were reported to be non-compliers as well and then chose one of the neighbourhoods to begin our interviews. Where possible, we informed the head of the village that we were there, showing him a letter from the District Health Authority which explained the research and who we were. Interviews were usually conducted in the early morning or late afternoon and early evening in order to reach people when they were home from the fields. We usually approached the first open house we came to, asking people if they would consent to be interviewed. If they did, we continued the discussion at a location of their choosing. After completing the interview, we walked to another part of the village to avoid interviewing small clusters of houses. In some villages, it was difficult to find non-compliers, and so we enlisted the help of community health workers or other villagers in doing so. Rumours of compliance and non-compliance, however, were not always true.

Respondents were read or given to read the information sheet and asked to sign the informed consent form at the beginning of each interview. Interviews were recorded with permission from the respondent onto a digital recorder. No names or addresses were recorded with the interviews or on the informed consent forms in order to ensure confidentiality. Respondents were given the information sheet for further reference.

I kept a daily diary of field notes to refer back to during analysis. My supervisor Professor Wellings was present during the beginning of the field work. Together we discussed the day's interviews and the various themes that began to emerge. As new topics were introduced, they would be incorporated into the following day's interviews.

#### **4.6.2. ANALYSIS**

Framework, a matrix developing method, was used as the system for ordering, synthesising and analysing the data from the 43 interviews (Ritchie et al. 2003).

Of the different approaches to analysing qualitative data, the Framework method was chosen to be the most appropriate for this research as it is “explicitly geared towards generating policy and practice-orientated findings” (page 184) (Green and Thorogood 2004). One of the important aims for the use of these research findings is to make concrete and relevant recommendations for the LF programme, so as to assist with improvement of compliance rates in communities. While this is an important aim of the research, as there is no present theory on individual reasons for compliance, the analysis of this data also includes, to a certain extent, theory building as well as theoretical understanding of the data by placing it within a broader theoretical perspective, in particular, social dilemmas (Spencer et al. 2003).

The Framework method provides a comprehensive method from which to interrogate the interview data on Alor and fulfils the criteria outlined by Spencer et al (2003) for maximisation of the qualitative analysis. The authors suggest that any chosen theory should 1) remain grounded in the data; 2) permit captured synthesis or reduce the data; 3) facilitate and display ordering and; 4) permit inter- and intra-case searching. The Framework method also provides a comprehensive view on the data, as both thematic and individual-level analysis can be done, once the matrix is complete. (Spencer et al. 2003)

### **Organising the data**

The first step in the Framework method involves the management of the data; rooted on the basis that “analysis is a continuous and iterative process” (page 219) (Ritchie et al. 2003). Once the interviews were done, they were transcribed in Bahasa Indonesia by an Alorese student in Kalabahi and by an East Timorese student in London. These students were requested to write word for word in Bahasa Indonesia the contents of the taped interview into Microsoft Word. (Due to time considerations, 12 of the interviews were not transcribed word for word.) The researcher conducted the analysis in Bahasa Indonesia, however there were 11 interviews which were summarised in English which could be shared with the advisory committee.

According to Ritchie et al (2003) familiarisation with the data, is an essential step in the first steps of data management. In order to do this, I read the interviews, referring to the taped version, while looking for emerging themes and categories. In addition, I re-read the field diary I kept every day during my field work which provided additional contextual notes which were useful in remembering the interview and factors which may have influenced the discussion. Furthermore, this diary provided me with insights I had on emerging themes during the field work. As I conducted the 43 interviews, I became increasingly familiar with the subject matter and was able to explore new themes as they arose with subsequent respondents. The combined results of this work provided me with a group of themes and categories which had emerged from the data; including knowledge, behaviour, memories, opinions as well as emotions.

This iterative process allowed me to develop a final list of emergent themes, which Ritchie et al (2003) call an initial conceptual framework, which would guide the development of the analysis matrix; the next step in the Framework process. When reviewing the interviews (transcripts and taped recordings), where necessary, I was able to add categories to the conceptual framework as needed.

As an example, I list below some of the following categories emerging from the data gathered during the interviews and familiarisation process which were used for the conceptual framework.

*Reported reasons for compliance*

- a. "Serf mentality"
- b. Reputation
- c. Influence of important or respected people
- d. Sanctions, punishment, force
- e. Gender
- f. Group norms
- g. Government (belief in / distrust of)

- h. Free provision of drug
- i. Fear
- j. Happiness and other emotions
- k. Traditional medicine
- l. Prevalence of LF disease
- m. Economic reasons
- n. Family
- o. Black magic
- p. Neighbours
- q. Priority of health
- r. "Prevention is better than treatment"
- s. Traditional health beliefs
- t. Knowledge

Following the creation of the conceptual framework, I read every transcript or listened to the tape itself and entered relevant comments into the matrices according to the framework shown above. Because the frameworks serve as a reference to the original raw data, I listed a line number or a time in front of comments so that I would be able to reference them in the matrices back to the raw data. This allowed me, during the writing process, full access to the original discourse so that the richness of these comments would not be lost.

I chose not to use a qualitative computer package for the analysis; rather I put the details into large Microsoft Excel spreadsheets. In order to further categorise the data, separate spreadsheets were created in Microsoft Excel for different thematic matrices, e.g. one for the themes arising from the interview discussion, one for the hypothetical situation drawings, one for the order of statements, one for the meaning of health and one for outliers to the existing conceptual framework. These outliers were generally comments concerned with traditional health beliefs not necessarily related to LF. For all matrices, the vertical axis listed the individuals through codes and personal descriptions. (See Appendices A.8 and A.9 for examples)

Once the themes emerged from the data, a further taxonomy of the categories was created to order them for easier analysis. For example, for themes related to the lay causes of aetiology, the data revealed causes which were outside an individual's own control versus causes which were within their control. These two larger categories were further broken down into those relating to the physical environment, behaviour, biomedical understanding, heredity and inherent susceptibility and supernatural causes.

In another example, themes related to coercion were further categorised into threats, moral punishment from peers and family, interpersonal pressure and positive sanctions and rewards. These themes in particular were discussed in relation to another context, tuberculosis control, by Richard Coker (2000) in his book "Chaos to Coercion: Detention and the Control of Tuberculosis." The themes arising from the 43 in depth interviews relating to coercion were grouped according to Coker's theories on coercion.

### **Analysis of the data**

#### ***Vertical analysis – by theme***

According to the Framework methodology, I carried out analysis both horizontally and vertically across the matrices. I began my analysis by looking at the data vertically, or across the themes themselves. This meant that I would not consider the individual's whole narrative; rather I was interested in the range and patterns in the responses seen across one theme or a set of themes. The steps which I discuss below were performed simultaneously, allowing me the flexibility to return back to the data where necessary and continue on the analysis following another stream of thought.

Some of the themes were further categorised for the purposes of analysis; for example, I combined the themes of reputation, group norms, family and neighbour into a social norms category. In this stage of the analysis, I was able to further categorise the responses and see how they reflected the theoretical

underpinnings of my research. In order to remain as objective as possible, my supervisor would also review the same set of themes. Afterwards, we discussed how we each categorised the findings and where discrepancies prevailed, we discussed until we reached a consensus, thus improving inter-rater reliability.

I also used associative analysis in order to reach a deeper understanding of the data, which included searching for links between two or more thematic occurrences. Called matched linkages, these provided me an opportunity to investigate, for example, whether compliers in general perceived the benefits of treatment to be good. (Ritchie et al. 2003) I also looked at sub-groups (Ritchie et al. 2003) within the data set, particularly within the themes of gender and level of education, to see if these sub-groups were inherently different from each other.

On finding associations, I checked them across the data set, sometimes counting their frequency. As in the Framework method suggests, numerical distributions are used “as a means, not an end, to gaining understanding” (page 251) (Ritchie et al. 2003). Numbers allowed me to see how commonly a certain association or phenomena recurred across the data set. I also considered those who were outliers to these associations and tried to understand why they behaved differently.

In order to explain some of the phenomena which emerged from the data set, I often reviewed the cultural context for further understanding. This entailed a separate literature search as well as contacting key informants who were able to provide me with additional insights which may have had some effect on the observation I had made. On occasion, I also referred back to the entire interview, checking the context in which something was said or looking at who the individual was and how that might explain the phenomena. I also drew on empirical data which came from similar studies in order to see how other findings fit in with my own, and where necessary, as Ritchie and Lewis (2003) suggest, borrowing concepts or explanations to shed light on a certain phenomenon.

Finally, I checked some associations and observed phenomena against the theoretical underpinnings of this research – namely elements of solutions to the social dilemma and some elements of the health promotion theories. As Ritchie and Lewis (2003) warn, the researcher should stay close to the respondent's language and accounts and not let the theory "bully" (page 257) the data. Following their recommendation, I looked at the theory late in the analytical process, seeing how it fit within the data, my observations and the research findings.

### ***Horizontal analysis – by individual***

In addition to looking vertically across the matrices, I was also interested in analysing individual responses (e.g. looking horizontally across the matrices). In order to do this, together with my advisory committee member Dr. Robert Auger, I devised a map which helped to understand how different factors identified in the thematic analysis interacted within an individual to identify the primary reasons for compliance (a 'causal chain' identified with a red line connecting the relevant factors to compliance). These maps have the following topographical features: external social world (people involved in the MDA); the disease environment (prevalence of LF); the event itself (MDA); personal characteristics (age, gender, occupation, education, current health status); knowledge about LF; beliefs about society; personal experience (with treatment and side effects) and; values.

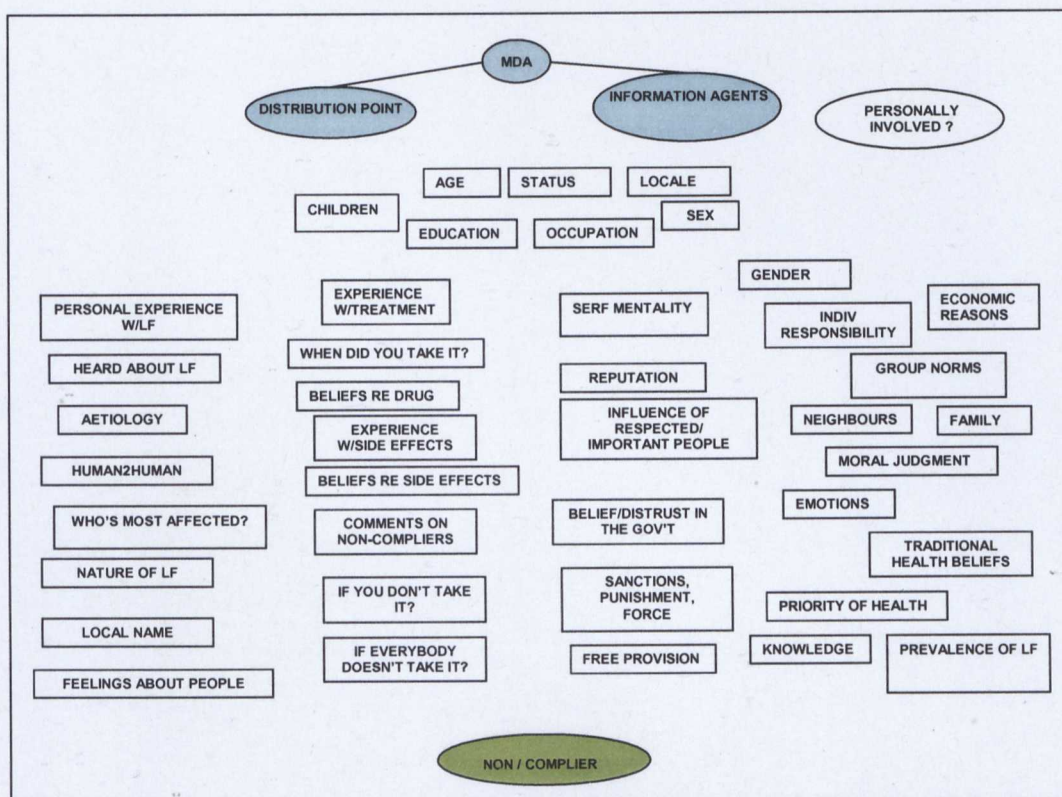
To explain the development of these 'causal chain maps for compliance' (CCMCs), I have outlined the process we took to arrive at the final map which was used for analysis. The process of developing the maps involved iterative changes over a year long period.

We reviewed semantic networks in general which have "the capacity of creating an encyclopaedia-like description of a culture" (page 63) (D'Andrade 1995). These maps can connect any selection of themes in order to present a picture of the research question at hand. We developed the causal chain of compliance maps with a more specific structure in mind which was relevant to the research



question on compliance and also included some additions from the field of psychology.

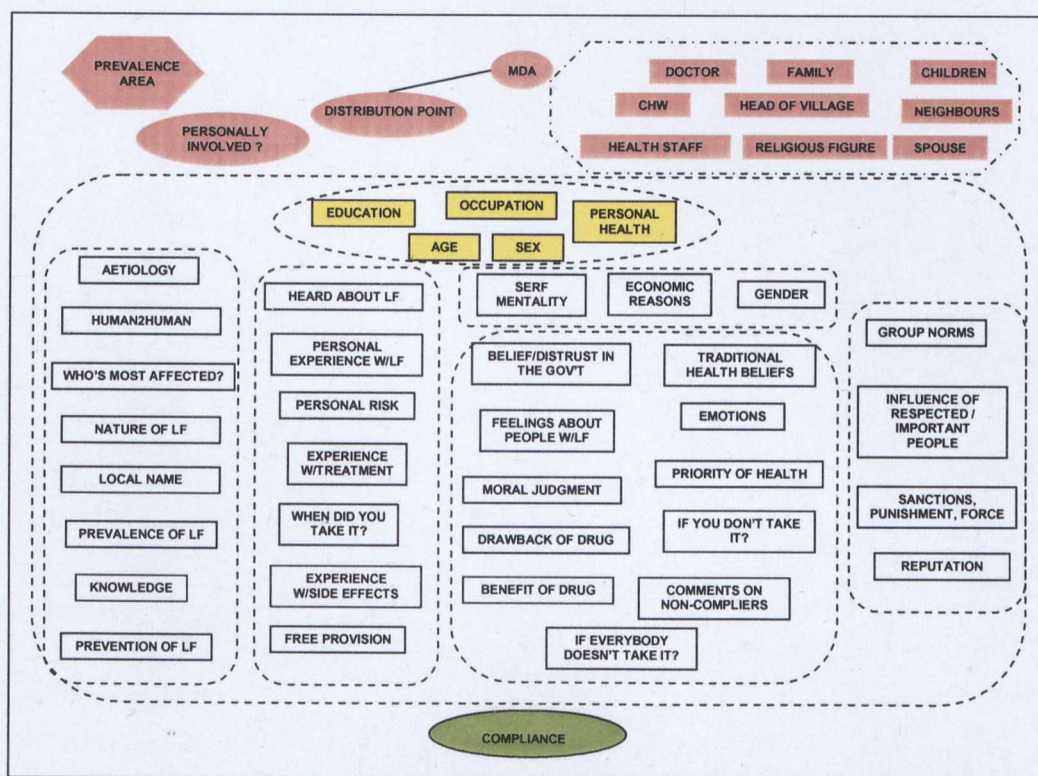
At the beginning of the process, each of the themes and variables was given its own box corresponding directly to the conceptual framework. These boxes hung freely in the map and were loosely grouped into “MDA”, “self”, “beliefs”, “experience” and “internal factors”. In order to illustrate a person’s decision about compliance, the interview data was reviewed and explicit links from the interview were used. For instance, if someone said “I am angry about people who did not comply with treatment for LF”, there would be a link in between the boxes “Emotions” and “Comments about non-compliers”. After all of the links were made, then the most direct or shortest route between the person or the MDA through the map and to compliance would be coded as the “red route” or the primary reason(s) for the person’s compliance or non-compliance.





After reflection and discussion, the boxes were consolidated into thematic sections, which better represented the variables. With the first maps, it was visibly difficult to differentiate those themes which were crucial to an individual's reasoning for compliance. This same problem is suggested in D'Andrade's book (1995) "the problem with such networks is that everything is connected directly or indirectly to everything else, so there is no clear way of grasping what is important and what is peripheral. Instead of having a small number of features which reveal what is important..., one ends up with a great encyclopaedia in which everything is as important as everything else" (page 63-4).

In order to improve the map's simplicity, the second version of the map contained groupings of themes according to the following categorisation: description of the MDA; description of the self; beliefs about LF; experience with disease; self-related factors; emotions and opinions; internal-related factors; the individual's decision – compliance or non-compliance.

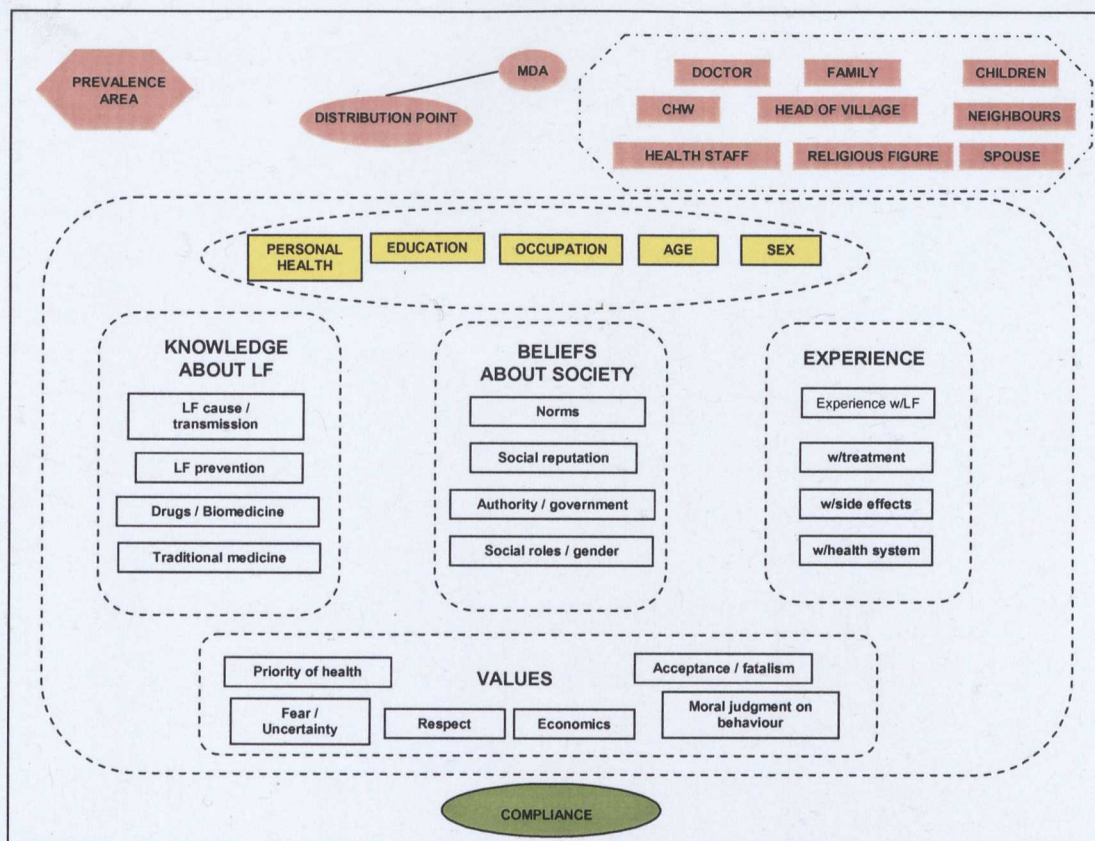


Here, the circle for expressing an individual's compliant and non-compliant behaviour was changed to the theme of compliance in general. With this change, came two significant shifts in the maps. First, instead of coding only a person's own routes to compliance, now all mentions by the individual of influences on compliance would be included. Only the person's own decision route to compliance would remain red. The second shift included only links related to compliance would be drawn; other associations would be ignored. This simplification made visual interpretation easier.

With the new version of the map, my advisor and I tried to code an individual's data independently in order to assess inter-rater reliability. After several attempts, we found that we could not reach over 50% reliability in our respective maps. There were several reasons for this lack of reliability. First, my experience and knowledge of the culture and LF situation in Alor influenced the way that I coded and implied interactions between variables were harder for me to ignore. Secondly, the variables listed on the map were open to subjectivity.

After much discussion, the maps were again revised in order to be more generalisable to disease control decision-making as well as to reduce the possibilities for subjectivity. This is the version which has been used for all 'horizontal' data analysis in the results:





Nine clusters of themes are represented here. Beginning in the upper left hand corner of the map, there is a hexagon for prevalence area. Depending on the location of the interview, this will be marked “high” or “low” prevalence to reflect the local disease environment with respect to LF. Moving towards the top centre of the diagram is the description of the event itself – the mass drug administration (MDA). The method of distribution is described in the circle called “distribution point.” In the upper right hand corner is a cluster of boxes which represent the individual’s relevant social world. They include the individual’s family, neighbours, community and religious leaders as well as the health staff in their village. Wherever the informant mentioned the involvement of a person in the MDA (promotion, distribution of drugs, education, etc.) there is a black line drawn from the event “MDA” to the kind of individual mentioned.

In the centre of the map, is a yellow oblong oval which contains the respondent’s individual characteristics: personal health status, education, occupation, age and gender. Where they did not mention something about their status with respect to

one of these characteristics, then the field remains as a general description only (e.g. personal health, education, occupation, age).

Below the individual's characteristics are three clusters of themes: "knowledge about LF", "beliefs about society" and "personal experience". These three clusters illustrate the internal knowledge and external experience an individual has about the drug, treatment and society around him. Specifically, the purple cluster of themes about "knowledge about LF", relate to: cause and transmission, prevention, drugs and biomedicine and traditional medicine. It is important to note that knowledge used here refers to everything the individual knows or believes about the disease and its treatment; rather than biomedical or correct knowledge specifically. The combination of interpreting knowledge and beliefs as equivalent concepts without judgment on correctness is recommended by Peltó and Peltó (1997) in their theoretical paper on studying knowledge, culture and behaviour (Peltó and Peltó 1997).

In the middle cluster, "beliefs about society", categories relating to norms, reputation, authority (including government) and social roles (including gender) are seen. These categories relate to the societal environment and its influence on the MDA.

In the green cluster to the right are the categories relating to the respondent's "personal experience" with the treatment, side effects and the health system. These experiences can be the respondent's own experiences, those they observed personally or those which they heard about. These experiences – whether felt, seen or heard – may have influenced a respondent's decision to comply.

At the bottom of the causal maps is a long red square with "values", namely priority of health, fear/uncertainty, respect, economics, acceptance/fatalism and moral judgment on behaviour. The list of these values is not exhaustive in terms of general values which exist, however these are the specific values which arose out of the interviews and are therefore included here.

Finally the green oval at the bottom called “compliance” refers to the outcome of the map – the act of taking the LF treatment.

Lines are drawn between the boxes in the diagramme if the respondent made an explicit statement linking two or more of these concepts or behaviours. The lines concern factors affecting compliance within the community or may reflect personal reasons for compliance or non-compliance. For example, if an individual said “people were afraid to come for treatment because of side effects” a black line would be drawn from experience with side effects to fear to compliance. This represents an individual’s opinion about what influences compliance in his/her community.

All lines are coloured black unless they form part of a line which stretches from the top to the bottom of the diagramme – that is, starting from the external environment (social world, description of the MDA or disease environment) or from the individual’s personal characteristics (age, gender, education, occupation, personal health), and reaching to the behaviour itself – in which case they are coded red. The red routes provide a complete causal explanation of the individual’s behaviour by showing a chain of factors accounting for the respondent’s entire logic from the stimulus of the distribution event to their response in terms of compliance. These red lines are called complete causal chains. The chain is composed of often independent comments in the interview which are only linked up once they are placed in the diagram. The value of the terminal links to compliance (reinforcing compliance or not, as determined by the meaning of the statement in the interview) should predict the behaviour which was actually reported (compliance with treatment or non-compliance with treatment). In cases where there are several complete causal chains, the greater number of values (positive or negative) predicts behaviour. It should be emphasised again here that the data itself determined how lines were drawn; and so the predictive quality of the maps is an emergent feature of the method, rather than a criterion of the coding.

Lines which are drawn from other factors to the compliance oval have a plus (+) sign or a minus (-) sign referring to a positive or negative effect on compliance by that factor.

Dr. Robert Aunger and I independently reviewed the data for 21 individuals (50% of the data set) and drew individual maps. Inter-rater reliability was high. These 21 individuals were selected purposively from the total sample according to the same criteria as the larger sample was drawn: compliance and prevalence area with equal representation of gender. We reviewed the 21 maps to see if there were any patterns which could be drawn from respondent's individual decision-making. We decided to conduct the maps for only 50% of the data set as this is an exploratory method which is new to the Framework analysis process.

#### **4.6.3. FACTORS ENHANCING AND HINDERING THE IN DEPTH INTERVIEWS**

Some factors made it easier to carry out the in depth interviews. As in the KAPB survey the year before, the government of Alor gave me *carte blanche* to conduct the interviews wherever I needed to; in fact they provided me with an official letter with the name of the villages left blank, for me to fill in. Their support extended to hosting me and our small team in the local health centres when we were in remote areas and needed to stay the night. Being a foreigner allowed me to interview people who may not have otherwise been accessible to me. As the interviews were carried out, it became obvious that I, as the foreign researcher, was a "safer" person for some respondents than an Indonesian outsider from the provincial capital. There was a history of trauma in the rural areas during past political elections when Indonesians from other islands came bearing gifts (we brought a towel and soap) and then registered the villagers with their signatures on a blank piece of paper (we asked people to sign the informed consent form). This paper was then filled in at a later time, saying that they were members of the Communist party. These same villagers who had signed the paper were later killed and their families ostracised. I was told that still to this day, they are not permitted to work for the Indonesian government. It soon became obvious that it was safer and more comfortable for the people to speak with myself, the

foreigner, who had no connection to these events in the 1960's and to trauma associated with Suharto's New Order government (See Chapter 5) . The hard feelings of these events still remain in places like Alor. As an interviewer, I was considered safe by some people I interviewed because I was far enough outside their system to be confidential; however I had enough experience there to be understanding of their culture.

There were however, down sides to being a foreigner at that particular time in Alor. We arrived there in the beginning of November 2005, just after a second wave of terrorist bombs on Bali the previous month. The police had been instructed that all foreigners needed to be registered at the police station within 24 hours of arrival on Alor. Even though I was there as a guest of the government of Alor, my supervisor and I still needed to comply with these regulations. What ensued was a 30 minute tense interchange with the local intelligence officers, which left us both feeling harassed and angry. The conversation turned when we mentioned that we were both living in England and home to David Beckham and Manchester United. Thankfully, David Beckham's prowess is known even at the far corners of this earth!

My previous participation in LF control in Alor was an advantage to the interviews, in particular the preparation ahead of time. I was able to connect immediately with the health service personnel both in Kalabahi and in the remote areas. This eased my entrance into villages and also provided me with useful information on where to find non-compliers with the MDA. Sometimes the health staff would alert me to an area in the village where a cluster of households which did not comply with the MDA were located. As well, we were asked to participate in two training sessions for local community health workers which were ongoing at the time of the pilot interviews in Apui and in a field visit in another area called Mainang. This allowed me to see first hand how the health services were continuing the MDA, four years after I had helped them begin the process.



One difficulty I did not expect was the working relationship with my research assistant. I had been advised during the course of my upgrading, that I needed to hire an Indonesian research assistant who would be able to aid me in both the Bahasa Indonesia language as well as help with cultural idiosyncrasies which I may miss the meaning of. I received several CVs for the position and finally settled on interviewing the person who had the most experience in social sciences and who was presently working on a PhD in linguistics. He was a man in his 40's, married and who interviewed well. He travelled to Alor and participated in the development of the topic guide so that he could understand why certain topics needed to be covered and how we would conduct the interviews. The first interviews that we did together were difficult and we tried to work through these differences of opinion before trying more interviews. It became apparent early on in the fieldwork, however, that I had more knowledge of the culture of Alor than my research assistant who had never been there before. His demeanour with respondents was sometimes abrupt and caused them to shorten their response. In addition, he was hampered in his ability to move around to the more remote villages due to his deep fear of the black magic present on Alor. Alor is rumoured to be one of the areas with the strongest black magic in the province and is indeed a significant part of their culture. His fears were real and meant that he was also less willing than I had hoped to approach people for interviews or to ask about the role that black magic may have in people's perception of LF or its treatment.

Another hindrance was my difficulty to communicate with a handful of respondents. They were generally older people who spoke limited Bahasa Indonesia. One particular gentleman is worth describing. We had been told that there was an older man living in the village of Dulolong who had repeatedly refused to comply. The community health worker told us that she would bring us to his house so that we could talk with him. As we began to climb the hill to his house, the rain began to fall and the path became dangerously muddy and slippery. When we finally reached his house near the edge of the town, we found an older man who lived alone. He was willing to be interviewed, but he would

not respond to any of the questions or even enter into a dialogue with me. The only thing he expressed was that he had been sick for the last 6 years and that it felt that worms were eating the insides of his stomach. The community health worker did not help in this particular situation. She insisted on remaining in the room with us and offered to help with translation into the local language. What transpired however, were her offhand remarks about how he was difficult and never communicated with anyone. Even if this gentleman had wanted to speak with me in detail, she sabotaged my interview. He certainly would not have trusted her translations.

This case is not isolated in its illustration of the difficulty of being able to interview someone alone. In Alorese and in Indonesian culture, being alone is undesirable and sometimes unacceptable. In addition, even though my being a foreigner made me a safer person to talk to, it also made me the focus of the village evening gossip. It was inevitable to have children peek their heads in windows or doors or people simply walking in and sitting down to join or listen to the discussion. In some situations I was able to say that I needed to speak alone to the respondent and they would understand and leave the room, and that was normally what occurred. There were of course, some situations where this was not understood and the interview became a public discussion between me and the person being interviewed.

## CHAPTER 5: RESULTS

### 5.1 SUMMARY OF THE DATA COLLECTED

The achieved sample for the series of 43 in depth interviews is presented in Table 4.

**Table 4 In depth interview sample**

	<b>Complier with treatment</b>	<b>Non-complier with treatment</b>
<b>High Prevalence area</b>	6 men (5 rural + 1 urban) 6 women (4 rural + 2 urban)	4 men* (3 rural + 1 urban) 4 women (2 rural + 2 urban)
<b>Low/No Prevalence area</b>	7 men (2 rural, 2 suburban, 3 urban) 5 women (1 rural, 2 suburban, 2 urban)	4 men (1 rural, 1 suburban, 2 urban) 7 women (3 rural, 2 suburban, 2 urban)

\*One man I have included in the non-complier section, although some of his comments suggest that he may have taken the pills so I have coded him as C37.

The respondents represented a cross-section of Alorese society (for a full description of their characteristics, see Appendix A.7.). The sample comprised 21 men and 22 women. Men's ages ranged from 23 – 70+ years (mean 42 years) and women's from 17 – 55 years (mean 36 years)<sup>10</sup>. The primary occupations of men were farmers (8) and civil servants (5), together with fishermen, labourers and those in private business. The women were primarily housewives (10) with five women having some occupation outside the home (pastor, weaver, sewing, traditional healer and community health worker). Of those who told me of their education level (26), the majority were elementary educated (12), followed by

<sup>10</sup> As is expected in interviews in such environments, some respondents were unable to give me their age or birth date. As a result, I estimated their age as someone in the 20's, 30's, 40's, etc. To calculate the mean age, I then estimated this person's age as 25 years. I had to estimate ages for 9 individuals.



junior high school (9), higher education past high school (3) and senior high school (2)<sup>11</sup>.

The interview locations also represented a cross-section of the physical and epidemiological environments of Alor.

**Table 5 Description of villages in which interviews were conducted**

Name of village	Distance from district capital (in hours by private car)	Environment	Kind of LF reported to be present	Number of interviews carried out
Apui	3	Mountainous, vanilla growing region	None	1
Ampera	20 minutes	Coastal	None	3
Dulolong	20 minutes	Coastal	None	3
Fanating	20 minutes	Flat land, rice growing	<i>B. timori</i>	6
Kalabahi	0	Coastal	None	9
Maritaing	6 hours	Coastal	<i>W. bancrofti</i>	7
Maukuru	4 hours	Coastal and mountainous	<i>B. timori</i>	1
Mausemong	8 hours	Coastal	<i>B. timori</i> , <i>W. bancrofti</i>	3
Mebung	30 minutes	Coastal	None	7
Tominuku	1 ½	Mountainous, rice growing	<i>B. timori</i>	2
Welai Selatan	1 ½	Mountainous, rice growing	<i>B. timori</i>	1

On average interviews lasted an hour, though some were longer. Three persons refused to be taped and these interviews were hampered by a difficulty in language and understanding (they spoke primarily local languages). As a result, their results were limited. For analysis purposes, 40 recorded interviews offered the bulk of the information for the findings presented below. As mentioned above (see Note to Readers), I use the codes NC and C to refer to non-complier and

<sup>11</sup> There are only 11 high schools on Alor, 5 government-run and 6 privately run (8 of these are located in the district capital) so these results are not surprising. (2003). Alor Dalam Angka 2003, Dinas Pendidikan dan Kebudayaan Kabupaten Alor.

complier respectively, and the subsequent number corresponds to the identifier in the Framework matrix.

## **5.2. LAY CONCEPTS OF CAUSE, TRANSMISSION AND NATURE OF LYMPHATIC FILARIASIS**

An understanding of people's perception of LF is of key importance in understanding influences on compliance with MDA. In this chapter, I describe respondents' concepts of the causes, transmission routes and the nature of LF, and I examine how their perceptions of the disease might affect their compliance with the MDA.

First, I briefly examine the *Bahasa Indonesia* words related to cause and transmission of disease. Describing cultural interpretations of contagion Caprara (1998) suggests that understanding the words used by people will help in understanding how they perceive the disease itself. The Alorese spoke to me in *Bahasa Indonesia* which was for both interviewer and respondent our second or third language; most Alorese would have grown up speaking at least one local language. Words used to convey cause included: *kena* (be touched adversely, struck, hit, or affected by something unpleasant, come into contact with, to get), *karena* (because), *dari* (from), *datang dari* (comes from), *tiba-tiba* (suddenly, unexpectedly), *pengaruh* (influence). [Translations from (Echols and Shadily 1997).] The words *tiba-tiba* appeared to be reserved for use in connection with black magic as a cause of disease.

Thus, concepts of causation and consequence featured prominently in the Alorese vocabulary. The descriptions suggest something coming from outside of the individual to strike him or her. It is interesting that people used these words to describe causes of the disease while in later discussions about the consequences of not taking the drug, the word *serang*, meaning to attack (Echols and Shadily 1997) was more commonly used. Attack is a more violent word and suggests a fight against the disease which all people should be involved in. In some cases, the language used suggested an anthropomorphic conception of the disease. One woman (NC9), for example, reported her husband having said "*the disease filaria*

wants to come to this village” (*mau masuk desa sini*); which seems to impute to LF both intention and motivation.

### 5.2.1. CONCEPTS OF CAUSATION

In the following sections, I organise the categories of concepts of causation according to the frequency with which they appeared in participants’ accounts. Factors mentioned included those relating to: the physical environment (27); behaviour (17); biomedical explanation (16); hereditary and inherent personal susceptibility (7); and the supernatural (3). 7 respondents were unable to say what the cause of disease was.

#### **Factors relating to the physical environment**

The most commonly mentioned causes of LF related to the physical environment summarised in Table 6. In two cases (NC23; C25) the environment was seen in terms of a specific region, that of Mainang, behind the mountain, the site of international research into *Brugia timori* from which images would have been broadcast all over Alor. More commonly, participants attributed the cause of LF to living, working or coming into contact with a certain kind of physical environment. Environments mentioned included rice fields, swamps, the wind, the mountains, and water, but the predominant environmental feature mentioned was mud. In implicating mud, it is interesting to note that no respondent made a connection between mud and the agent of transmission – the mosquito; rather they interpreted mud (contact with, animals in the mud, etc.) as directly causing LF. Instead, in their references to swamps, rice fields and mud, they focussed on what were effectively mosquito breeding areas. Some, however, (C19; NC52) did extend the explanation, describing caterpillars or larvae in mud.

It is perhaps not surprising that the majority of people living in both coastal and mountainous (including inland) areas mentioned rice fields and the mud associated with them as the main cause of disease. In mountains and inland areas where *B. timori* is present, the *Anopheles barbirostris* mosquito breeds in either fishponds or rice fields (Idris-Idram 2002). Since rice fields are the main breeding place for *Anopheles barbirostris* mosquitoes, it is easy to understand why

respondents were able to make a connection between rice fields and contracting LF as a result of their collective and cumulative observations. Thus, despite the fact that for some, elements such as wind and water may have had supernatural connotations, the thought process was a rational one, observation being a key element in the scientific method. People in coastal areas would have heard about people living in the rice field areas of Alor where there is an increased prevalence of LF and indeed told me of seeing such people with lymphoedema in markets and knowing family or friends who have had contact with infected people from these inland areas. Furthermore, the *Anopheles subpictus*, is found primarily in coastal areas where *W. bancrofti* is found, and likes to breed in brackish water rather than rice fields (Supali et al. 2002).

For those living in the mountainous and inland areas where rice fields are more prevalent, all but one (C21) mentioned the environmental cause of disease as rice fields. The fact that less mention was made of swamps as a cause of LF is not surprising as there is less disease in the coastal areas and what there is, generally chronically manifests in the form of a hydrocele which is less visible than lymphoedema or elephantiasis of the leg. People were less likely to make the connection between disease and swamps in the case of bancroftian filariasis than they were to make that between disease and rice fields in the case of brugian filariasis, whose primary chronic manifestation on Alor is lymphoedema of the leg.



**Table 6 Respondents' perceptions of cause of LF in terms of physical environment\***

Individual	Rice field	Mud	Swamp
Man, 48 yrs, civil servant (C5)	From the rice fields		
Man, 38 yrs, fisherman (C10)	From the rice fields		
Man, 35 yrs, private business (C14)		Walking in the mud	
Man, 30 yrs, farmer (C19)	From the rice fields	Caterpillars / larvae in the mud which if you don't bathe after you get home, the symptoms will appear	
Man, 30 yrs (C21)			Swamps where there are faeces and garbage thrown in and the water stops flowing. If not bathing after getting home, then will get it.
Woman, 25 yrs, housewife (C53)	Working in the rice fields		
Woman, 53 yrs, housewife (C55)	Working in the rice fields because there is a lot of mud		
Woman, 51 yrs, housewife (C57)	In Fanating and Bukapiting <sup>12</sup> , people work in rice fields and the mud is not compatible, so maybe they already have LF in their bodies and it comes out. They walk in mud and it comes out directly swollen.		
Man, 41 yrs, university educated (C49)		Animals (wild pigs) enter the mud	
Woman, 49 yrs (C54)	Going into rice fields and swamps		
Man, porter at seaport (NC13)		From mud (leg swells in mud)	From swamps
Man, 23 yrs, farmer (NC16)		Yellow mud with tiny reeds in it which you walk in	
Woman, 41 yrs (NC23)	The disease likes wet areas (it enters through your toenails, sores or pores)		
Woman, 24 yrs, housewife (NC24)			Walk through swamps where water spinach grows or in water tank water (it enters the stomach through the legs)
Man, 25 yrs, contract labourer (NC26)	Mud in rice fields which is black with grass		
Woman, 17 yrs, orphaned (NC29)	Working in the rice fields because there is a lot of mud – you walk in there and the legs start itching		
Man, 57 yrs, retired teacher (NC51)		From the mud which enters the body through the pores of the skin	
Woman, 53 yrs, housewife (NC52)	Working in the rice fields (there are worms there) and stomping down in the mud – now there is a machine for this – so there are no more cases		

\*Green shaded areas refer to compliers.

Other participants associated LF directly with water (C25, NC39, C42), and some specified water in high prevalence areas. A farmer from Mebung (C25) held that

<sup>12</sup> Two inland towns where there are large rice fields and where there were high numbers of cases of LF (B. timori).



if you walk in the water that has been in the sun in Fanating<sup>13</sup>, the leg starts to itch until it is swollen. In a similar manner, a woman from Maritaing (C42) told me that in Mausemong<sup>14</sup>, the water is yellow and *boa besar* is caused from using that water.

Other participants thought the wind was responsible for transporting the disease (NC9; C15; NC23). In some cases, the emphasis was on the wind bringing the disease to an area, while others mentioned the lack of wind as a factor in transmission of disease.

A woman (NC9) from Lewalu reported:

*It is often said in this village that here many diseases come from the wind... we do not know today that even God will maybe be fair; also a speedy wind or dirt can be brought today. It is said that today we can get [LF] if we do not take care of ourselves in terms of our cleanliness. But if we already have the medication, hopefully we can prevent this...*<sup>15</sup>

She adds that the wind is from the next door village, and from the east, west and south. Similarly, another woman from Mebung (C15) recalled having heard that there was a disease (LF) from outside of the country which was brought by the wind. She personally had never experienced this wind, but she explained how everyone must comply because of it. In another case, the emphasis was placed on the wind taking the disease away from an area. A woman from Mebung (NC23), for example, explained that there was more LF in the mountains because they have wet areas there and the air does not change as much as it does at the sea (where the wind blows more frequently). Because the mountains are far from the sea, she added, people have less salt in their bodies. In her opinion, the disease goes away in the body when it comes into contact with salty water, so people at

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<sup>13</sup> High prevalence area for LF due to *B. timori*

<sup>14</sup> A neighbouring community to Maritaing where there are many cases of LF due to *W. bancrofti* and *B. timori*.

<sup>15</sup> "Itu sering kayak dari desa sini dibidang desa katanya disini banyak penyakit dibidang dari angin....tidak tau hari ini Tuhan pun mungkin adil juga angin kencang atau apa kotoran bawa bisa juga hari ini bisa kena bilang kalau seandainya kita tidak rawat diri jaga diri kebersihan tapi kalau sudah dapat obatnya mudah-mudahan pencegahan kayak gitu."

the beaches cannot get LF. This third woman believed that wind in her village cleansed the air; that because there is less wind in the mountains, there is an increased likelihood of disease. Again, in making a connection between the wind and salty water and the disease, these participants can be seen to be using powers of observation and drawing from them simple associations. Mosquitoes are less apparent in areas of high wind and do not breed in salty ocean water.

### **Behavioural-related causes**

A further category of causes contains those related to behaviours likely to influence susceptibility. These include neglecting maintenance of health; specific kinds of activity (like swimming, climbing, scratching); and consumption of food and water. Two people (C15; C57) mentioned that attitudes may cause LF, by specifically saying that discriminating against people with LF (C15) or treating them as if you were nauseated by their condition (C57) will cause you to get the disease.

In terms of health maintenance, several people believed that not taking care of oneself would be likely to cause LF (C36; C4). One woman, a young pastor (C4) elaborated on what this meant in this context, which is, not taking care of infection and not observing rules relating to cleanliness giving the example of farmers coming home tired after work and not bathing before bed.

A sizeable group of people saw the cause of LF as related to food and drink (C10; C15; NC39; C41; C54; C55). Most commonly, the precise link was not described, though reference was made to consuming salty or sweet food or drink, and also to eating yesterday's food. Such notions are perhaps not surprising considering that there have been past public health campaigns in Indonesia to make sure that food and drink are prepared safely. I probably drank prepared water in nearly every village I went to and was never ill as a result. It is accepted practice throughout Indonesia to boil water and people understand that badly prepared water causes illness.

A link was also made between overworking, or over-exertion, and contracting LF (C57; NC34; NC28; NC39; NC43). Again, these explanations may be seen to be based on observation. Over exertion can cause the onset of adenolymphangitis which is associated with LF and manifests as an intense fever lasting several days. In addition, some people may have confused a hydrocele with a hernia, which would explain the association between hard work and *boa besar*. In Maritaing, the type of LF present causes hydrocele so it is possible that the answers from two people in that area refer to either a hernia or to a hydrocele. A 28 year old man from Maritaing (NC43) explained:

*Man: Before it is because we walk a lot, then we don't rest enough, and we work a lot for example, then we come home exhausted, work until we are exhausted and then we go straight to the sea to swim, climb trees...*

*Interviewer: And it wasn't like that for your ancestors as well?*

*M: That was a hereditary disease. You can't get rid of it. Sometimes there are also hereditary diseases.<sup>16</sup>*

Other behaviourally-related causes of LF mentioned include scratching and itching (NC34); having coffee or *tuak*<sup>17</sup> (C35) and sitting for too long (C40).

### **Biomedical concepts**

Of the 43 people interviewed, only a handful gave responses relating to the cause of LF which approximated to the accepted biomedical explanation. Such people were more likely to be more highly educated and were community leaders, community health workers and graduates; yet they also included some people with no educational qualifications. The most accurate responses, not surprisingly, came from the previous head of the LF control programme (C6) and a community leader in Fanating (C30). They both described the presence of worms in the blood and the head of the LF programme went on to explain the presence of microfilaria (mf). A university educated man living in Kalabahi (C49) told of a

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<sup>16</sup> *M: Awalnya itu dari kita banyak jalan, terus kurang istirahat, banyak kerja misalnya, terus baru pulang cape-cape, kerja cape-cape, langsung kita ke laut untuk berenang, tanjakan pohon.*

*I: Tapi dulu nenek moyang tidak begitu juga?*

*M: Itu ada penyakit turunan. Tidak ada bisa*

<sup>17</sup> A locally brewed alcoholic drink brewed from palm trees.

story handed down about a worm living in the mud that sucks blood and enters the body through the skin. This explanation is partially true – the worm does indeed enter through the skin; however it does not suck blood and live in the mud. A community health worker (NC12) told me that the disease was caused by worms in the stomach. Her response may have been influenced by her knowledge of the benefits of Albendazole (which rids the body of five different kinds of intestinal helminths). A fisherman from Ampera a coastal village outside of Kalabahi (C10) had also heard the disease comes from worms.

### **Heredity**

Several respondents believed that LF was a hereditary disease. This belief seemed to be more common where there was no apparent environmental cause. For example, one woman reasoned (C15) that it must be hereditary since there was no swampland present in her village. Common features of the disease for those who saw heredity as the cause were its inevitability and its incurability. A man (NC43) from Maritaing saw LF as a hereditary disease which, if present since childhood, would persist into adult life without any possibility of a cure. A 57 year old man from Maukuru (NC50) told me that both *boa besar* and *kaki gajah* were hereditary and that you could not get away from it if you have a family member who was infected. Another 57 year old man from Kalabahi (NC51) told me that LF was hereditary because people lived in mosquito areas for a long time. This has logical appeal since if, a mosquito takes a night blood meal from an infected father, the mosquito will rest and then feed on its nearest food source – which may be another family member asleep in the same room. Repeated many times, eventually one of those individuals may become infected with LF, giving the semblance that the disease has a hereditary component since more than one individual in the same household becomes infected.

Related to the idea of heredity, was the belief that the cause of LF could be traced to ancestors' actions. Here, however, the link to ancestors is more extensive and refers to generations of people, rather than an infected father or grandfather. A young girl in Fanating (NC29) explained that the disease comes from ancestors with LF; adding that the Dutch brought the disease to Alor during colonial times.

Relating the disease to distant ancestry, as opposed to immediate family, seemed to leave open possibilities for intervention or cure. As a woman from Mebung (C15) explained to me “*it was maybe from something our ancestors did*”<sup>18</sup> adding that it is possible to be free from this by Christianity (now prevalent in Alor) or governmental action.

### **Inherent personal susceptibility**

There is what may be a unique belief in Alor which determines whether or not you are inherently susceptible to diseases in general. A concept I heard about a great deal in Alor related to sweet or bitter properties of the body. Some spoke of it in relation to skin (*kulit*) and others to blood (*darah*), but the concept was the same. The idea is that people with sweet (*manis*) skin or blood are more susceptible to disease than people with bitter (*pahit*) blood or skin. As a 41 year old woman (NC23) from Mebung explained:

*Ya, I have even heard about it [sweet and bitter blood], if someone is less infected or not very infected, then they have bitter blood; but if someone is easily infected, then they have sweet blood, but I am not a specialist in this area, I just say what I think it is.*<sup>19</sup>

Asked how one could tell whether a person had sweet or bitter blood, a man from Mausemong (C38) replied:

*I will give you an example I have. I get a skin fungus because maybe my body, my blood is maybe sweet – it doesn't go away, and it stays with me. I don't know why, maybe I have sweet skin which is why it stays with me. But there are people who don't have it, maybe their blood or skin is bitter, so they aren't attacked like that.*<sup>20</sup>

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<sup>18</sup> “*Itu mungkin dari kita punya ini apa perbuatan bapak dari turunan...*”

<sup>19</sup> *Ya memang saya pernah dengar ada bilang memang kalau orang yang kurang terjangkit tidak terlalu terjangkit penyakit itu dia punya darah pahit tapi kalau orang yang mudah terjangkit itu darah manis tapi entahlah saya bukan ahli kesitu jadi saya cuma kira saya pikir saja begitu.*

<sup>20</sup> *Bisa, saya kasih contoh saya punya, saya kena panu karena tubuh saya mungkin, darah saya mungkin manis, dia tidak hilan, dia tetap saja. itu saya tahu persis, mungkin saya punya darah manis jadi dia tetap ada. Tapi orang yang tidak ada itu, mungkin darah atau kulitnya pahit jadi tidak dihindari begitu.*

Another explanation was given by a man in Welai Selatan (C21) who attributed the difference in susceptibility to disease between himself and his wife to this same phenomenon:

*...for example I am with my wife together everyday in one house in one room except that for example I get [a disease] and my wife doesn't; so people will say that I have sweet blood and my wife has bitter blood because we live together but one gets it and the other doesn't.<sup>21</sup>*

These explanations came from three completely different regions of Alor (a suburban village near Kalabahi, a mountain village in the interior and a village on the eastern coastal part of the island). All describe inherent characteristics which make an individual more or less susceptible to a range of diseases. Some also mentioned that having sweet or bitter blood/skin made you more or less susceptible to bites from insects or snakes. A man from Fanating (C30) explained to me that the way you knew if you had sweet or bitter blood was when a snake bit you:

*... people say 'oh sweet blood, bitter blood' because often if someone goes out and a snake bites him and the snake dies, then people say that person has bitter blood. If the snake goes and bites someone but the snake doesn't die, and keeps on running instead while the person gets the poison, until he swells up, then this person has sweet blood.<sup>22</sup>*

In a similar vein, a head teacher from Maukuru (NC50) explained that mosquitoes will not bite people with bitter skin. I was curious as to whether any moral judgment might be attached to the kind of blood that you had. The community leader I interviewed in Fanating (C30) said this was not the case: "No, those with bitter blood or sweet blood, all people are good."<sup>23</sup>

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<sup>21</sup> Itu orang tua misalnya saya dengan istri saya sama-sama setiap harinya disatu rumah satu kamar cuma misalnya saya yang kena istri saya tidak kena berarti orang akan sebut bilang saya ini darah manis istri saya pahit begitu jadi biar hidup sama-sama yang satu kena yang satu tidak biasanya begitu.

<sup>22</sup> Hanya orang katakan bahwa oh darah manis darah pahit karena dia sering pergi, ular pagut dia ular mati, makanya orang katakan darah pahit. terus ular yang terus pagut atau gigit sama dia, ular tidak mati tapi ular lari terus tapi dia yang kena racun. dia itu sampai bengkak, berarti orangnya darah manis.

<sup>23</sup> Tidak, yang darah pahit atau darah manis semua orang baik.

I asked if it was possible to change the kind of blood you had, since presumably everyone would prefer bitter blood to avoid disease. The woman from Mebung (NC23) was unsure; the man from Fanating (C30) said that you could not; and another participant (C38) told me that even if you were able to change your blood (for example through a transfusion), it would not make any difference since you had already contracted a disease when you had sweet blood. The only way to cure an infection was to take medication for it.

So if it was virtually impossible to change the kind of blood that you were born with, was there anyway to offset the vulnerability conferred by having sweet blood? Responses to this question, mainly related to the eating of foods thought to have the capacity to change from sweet to bitter. A man from Maritaing (NC43) explained that depending on the type of blood you had, avoidance of certain foods would reduce your chances of getting disease. With his blood (sweet blood) he said, eating goat's meat would cause an increase in his blood pressure, but he claimed it did not matter whether you had sweet or bitter blood when it came to *boa besar* (hydrocele), that people with either type could contract the disease.<sup>24</sup> Another man (C25) from Mebung told me he needed to eat bitter food, like papaya leaves, in order to counter an infection, adding that he could never eat anything sweet.

The concept of sweet and bitter blood/skin reveals an individual's inherent susceptibility to disease. It is not possible to change your own condition and you are able to know of your own characteristic only after you are adversely affected by the consequences. There is a parallel to this phenomenon in Mildred Blaxter's reports from Scottish women, of people being attacked by disease because of inborn traits (which were not inherited) and which she explained as an "inherent 'weakness'...simply characteristics of the person, parts of identity...there was nothing one could do to avoid them..." (page 65) (Blaxter 1983) Rory Williams (1983) found a similar pattern in elderly persons living in Aberdeen who identified a common part of the body as "the seat of weakness" (page 191)

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<sup>24</sup> This man's logic fits into his understanding about the causation of the disease, which is primarily behaviour-related or hereditary.

in a person's constitution which collect diseases or symptoms (Williams 1983). Despite having some similarities with both Williams' and Blaxter's findings, this data suggests that although people know that they could not change the kind of blood they were born with, they could nevertheless intervene to change its nature (e.g. by eating certain foods) and modify its effects by taking medication.

### **Supernatural causes**

Black magic plays a significant role in daily life on Alor and has been incorporated into current religious beliefs. Because of the secretive nature of black magic, I was cautioned not ask about it directly with respondents unless they mentioned it first. Only three people I spoke with talked directly of religious or supernatural causes of disease – animistic or magical – as a cause of LF infection or of death related to LF. I believe more may have considered black magic as a cause, but discussion about it with me may have been awkward. I often wondered how my foreignness may have influenced this since I heard many stories about black magic while I was in Alor and knew it to be prevalent. I was told by my research assistant that I had a *tubuh bersih*, translated literally as 'clean body'; which meant, within the context of magic, that I did not cover myself with any kind of magic, that I was bare. As a result, it would mean that I would be a 'safe' person to discuss such issues with as I would have had no agenda, ulterior motive or risk that I would send a spell myself. However, in spite of my *tubuh bersih*, it remained difficult to raise or discuss the subject of magic; rather I had to look for veiled references to magic (like mention of wind, air, *tiba-tiba*). In fact, Cora Dubois (1944) described a similar experience in Alor during her research 60 years ago, "It was very difficult to get any concrete data even from those willing to discuss the matter [referring to witchcraft and poisoning]" (pages 172-3).

DuBois observed that a frequent form of malevolent activity on Alor consisted of curses directed by one individual against another (DuBois 1944). This practice continues today, as explained to me by one of my research assistants, Daniel Obetnego. People put spells around their plantations to prevent people from



stealing their produce<sup>25</sup>; the curse for stealing is the development of a hydrocele, one of the long term manifestations of LF.<sup>26</sup> As a Catholic nun who had worked in eastern Indonesia for over three decades informed me, the concept of vengeful action remains strong on Alor. Terms like “*orang bikin*” or “*orang jehat*” are used to refer to someone, alive or dead who wishes another ill<sup>27</sup>. It is also possible that the ancestors are angry and cause something bad to happen (“*nenek moyang marah*”<sup>28</sup>). Numerous stories pervade the Alor region concerning bad spells and their effects on people. During my research in 2005, a child was born in a mountain village with no arms and no legs. Otherwise, the child was in perfect health, but his community nevertheless exiled him from the village because it was believed he had been cursed.

One of the respondents, a 25 year old non-complier from Fanating (NC26), believed that LF was caused by a curse. During our discussion however, he mentioned that there were actually two causes for the disease – mud and black magic. It is interesting to note that he was able to accommodate two causes for LF infection simultaneously. We enter this discussion after he has already mentioned the cause of LF being from walking in mud:

*I: In your opinion, how does this disease enter from the mud into the leg?*

*R: When he walks in the mud initially it sticks to him right away, when he steps in the mud, he has bacteria that enters and even sticks.*

*I: How does it enter?*

*R: Through small pores.*

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<sup>25</sup> Other spells from one area in Alor, Takalelang Abui to protect property include: (1) *boi upi* (in Malay: *kelumpung*) ‘literally the boi tree fruit’ for swollen testicles of the size of the boi tree. The fruit of the *kelumpung* tree is placed around the tree that is protected by the magic. (2) *fiyai* or candlenut (in Malay: *kemiri*), the candlenut placed by a tree or field will cause swelling of the neck and suffocation, (3) *wi bikat* or pebble stone which has similar effect as (2). There is a protective magical treatment that involves washing of the body with water and rubbing the swelling with lime. (Personal communication with Dr. František Kratochvíl)

<sup>26</sup> It is also an interesting commentary on gender as the curse for stealing is hydrocele, which only men can get. This punishment assumes that the only perpetrators of theft are men.

<sup>27</sup> Literally translated, *orang bikin* means a person who caused something and *orang jehat* is a mean person.

<sup>28</sup> Literally translated *nenek moyang marah* means the ancestors are angry.

*I: In your opinion, apart from mud, is there another way that you can get this disease?*

*R: There is a time where people use the technical term for magic to lose one's way which is given to cause people to lose their way. It's like that. There is a kind of esoteric knowledge that is given for causing people's to go astray with these methods.*

*I: Why would they give this disease to people?*

*R: The reason is that maybe they are basically jealous of someone's attainment in life, here.*

*I: Are people afraid because of it?*

*R: Ya, people are afraid because of it.*

*I: Can you prevent it?*

*R: It is a difficult disease to prevent.*

*I: Can you know whether it is from the mud or from the magic?*

*R: You can know if it is from magic or from mud, the two of them. If from magic, it will come from nowhere all of a sudden and there will be swelling. If from the mud, people's symptoms [come] when they want to work in the rice fields, and the disease attacks....<sup>29</sup>*

A 50 year old man from an endemic area, Maukuru (NC50), told me that *boa besar* (i.e. hydrocele) is a consequence of illegitimate entry to another person's land or crops. He added that some say that this is no longer the case anymore, but he himself is not sure. His comments mirror comments reported above relating to

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<sup>29</sup> *I: menurut bapa bagaimana penyakit ini dari Lumpur masuk ke kaki?*

*R: waktu dia diinjak baru ia langsung melengket memang, waktu injak itu dia punya bakteri tuh langsung masuk dan melekat memang.*

*I: dan dia lewat?*

*R: lewat pori-pori*

*I: menurut bapa selain lewat lumpur, apa ada cara lain untuk bisa kena penyakit itu?*

*R: ada kalanya orang pakai istilah ilmu sesat yang untuk kasih sesat orang. Sepertinya begitu. Ada sejenis ilmu yang untuk kasih sesat orang dengan cara2 itu.*

*I: kenapa mereka kasih penyakit ini ke orang?*

*R: artinya mereka mungkin baku iri toh, di sini*

*I: orang takut karena itu?*

*R: Ya, orang takut karena itu.*

*I<sub>1</sub>: Apa boleh mencegah?*

*R: itu penyakit sulit baru bisa cegah, sulit.*

*I: apa bisa tahu itu dari lumpur atau dari ilmu?*

*R: bisa tahu dari ilmu dan bisa tahu dari Lumpur, keduanya, kalau dari ilmu itu tiba-tiba saja membengkak, kalau dari Lumpur gejala orang mau kerja di sawah terjangkit penyakit tuh jadi ada jenis itu.*

the protection of land and crops through curses. A curse is usually clearly indicated on the private property by the presence of a red cloth tied to a nearby tree.

A community leader from Fanating (C30) spoke about how people in the past who would become sick and were unable to afford to go to the health centre or hospital because it was expensive and too far away. As a result, they would die of LF or malaria and the people would say that the death was a result of poison, “*setan*”<sup>30</sup> or a curse which killed them, rather than a disease. He associated these concepts with people who were less educated; people who were more educated and modern would go to the hospital. He told me that black magic itself had no relation with LF, only with death. Interestingly, he did not discount the existence of black magic; he only removed its association with LF.

Other participants made veiled references to black magic. A 28 year old man (NC43) believed that LF infects through eating and drinking, specifically through cooking leaves with snake bites on them or rice with dirt in it, but it was the contact with snakes and dirt that were seen as causing the illness. Snakes can have a reference to black magic (DuBois 1944). The earlier references to wind (NC9; C15; NC23) could also refer to black magic as curses can be brought by wind from other areas.

### **Scepticism and lack of knowledge**

Some people reported having no knowledge of the aetiology of LF (C42):

- Woman, 7 children, 55 years old, Maritaing (C42): *I don't know because no one talks about it so I don't know from those who have it how you get it.*

Others (NC28; NC/C37; C38; C40) claimed they did not know, despite having received information from health care professionals:

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<sup>30</sup> *Setan* literally translated is satan, the devil or someone evil.

- Woman, ~50 years old, married with 6 children, primary school educated, Fanating (NC28): *I don't know. It is not mud. I have been working there for years and my legs are normal. The health people say that it is from mosquitoes. Maybe it is from the environment. I don't understand.*
- Man, farmer, 2 children, 40+ years old, Mausemong (NC/C37): *I think that it is from another cause. In the opinion of the [health] staff it is from mosquitoes, filarial mosquitoes. They gave an example that the mosquito arrives and takes blood and brings it from humans. That's the analysis of the medical staff. Though we the people are still not clear about it – from where we don't know, this is a mosquito area.*
- Man, head of neighbourhood, 37 years old, primary school, Mausemong (C38): *I don't really know yet [where the disease comes from], but the explanation of the doctor's opinion was that it came from mosquitoes, if there is another way, I don't know yet.*
- Man, 43 years old, farmer, primary school, Maritaing (C40): *I don't know, but according to the doctor, it is from mosquitoes.*

These statements reveal some scepticism relating to scientific explanations provided by health workers. Why would people be reluctant to believe them? One possible reason is that these are mainly people living in LF endemic areas and so have already formed their own opinions about LF and aetiology of disease through a lifetime of experience around infected people. Disbelief may also result from their own observations that the disease had not affected them personally despite their local area being low lying and inhabited by mosquitoes. These people would have also likely been exposed to the mass drug administration with its team of health staff, films and posters. Some people, after seeing and hearing new information would have amalgamated it into their existing belief system. Others may have simply refused to believe that the new information was correct, preferring to maintain their own beliefs.

Mildred Blaxter (1983) made similar observations in her work on causes of disease among women in Scotland where the women were informed by their doctors about a particular cause of disease. She suggested that "...sometimes, of

course, they [the women] preferred their own causes: in particular, they were reluctant to give up ideas about familial tendencies, or about environmental causes, when their own evidence seemed to be so good.” (page 68) (Blaxter 1983) Similarly, Alorese people living in endemic areas have their own established theories of disease which they may be reluctant to give up.

### **Multifactorial causes**

Respondents often held more than one factor responsible for causing LF. For example, one woman (C15) stated at different points in the interview that she believed that LF was caused by inherited factors, attributing it to the actions of villagers’ ancestors; while at the same time she implicated the wind, punishment for discrimination against people with LF and poor eating habits. A man (C10) held it to be, on the one hand, caused by worms, and on the other by neglect of cleanliness; whilst a third man (C19) combined working in the rice fields, a mosquito vector and poor personal hygiene in his model of causation. These individuals list not one cause for disease; but several simultaneously. There are parallels here between the multifactorial explanations of these respondents and those of epidemiologists and clinicians attributing infection to the initial presence of pathogen, combined with individual susceptibility and further risk factors, such as neglect of preventive action.



**Table 7 Respondents' beliefs about aetiology, transmission and progression of LF disease**

<b>Code and characteristics</b>	<b>Aetiology of disease*</b>	<b>Transmission</b>	<b>Progression of disease</b>
C4: Woman, 20's, pastor	[H, B] Hereditary, not taking care of health, poor hygiene		Genital area itches, swollen genitals/leg
C19: Man, 30 years, farmer	[BM, E, B] Mosquitoes, rice fields, mud, poor hygiene	Mosquitoes	Swollen leg + arm, fever
C20: Man, 28 years, farmer	[B, E] Following someone /LF into mud, sleeping next to someone w/LF	Mosquitoes, mud	Itching, big leg, fever, asymptomatic
C21: Man, 30 years	[E] Swamps, rice fields, mud	Doesn't transmit	Fever, itching, swelling
C30: Man, 41 years	[BM, E, S] Mosquitoes, swamps, LF the blood (worms) ; refers to supernatural causes for others	Mosquitoes	Fever, itching leg, swelling
C35: Woman, 28 years	[B] Working hard, walking a lot, drinking coffee + local alcohol (tuak)	Not human to human	Fever, swelling in the groin, body uncomfortable, stomach swells, testicles enlarge
C36: Woman, 32 years	[B] Not taking care of health		Enlarged genitals for men, kidney, large leg, fever
C40: Man, 43 years, farmer	[D, B, BM] Doesn't know - doctor says from mosquitoes, sitting with a dizzy head		
C41: Woman, 28 years, weaver	[E, BM, B] Water and mosquitoes, swamps, washing and cooking with salty water		
C42: Woman, 55 years	[D, E, BM] Doesn't know, maybe mosquitoes or water		
C53: Woman, 25 years	[E, BM] Mud, rice fields, mosquito bites	Soap can transmit from person to person	Leg swells + coral-like formations
C54: Woman, 49 years	[B, E] Eating, rice fields, little bacteria	Transmissible disease, mingling w/ people w/LF, swamps	Itches
C5: Man, 48 years, civil servant	[E] Rice fields	Doesn't know	Big leg, sores
C6: Man, 70's, civil servant	[BM] Worms and microflaria	Mosquitoes	
C10: Man, 38 years, fisherman	[BM, B, E] Worms, poor hygiene, rice fields		
C14: Man, 35 years, private	[E] Mud	Doesn't know	Swollen leg
C15: Woman, 38 years	[E, H, B] Wind, hereditary, actions of ancestors, discrimination against people w/LF, food + drink		Swollen leg + large breast
C25: Man, farmer	[E] Mainang, air, water, mud, mosquito breeding area	Mosquitoes	Swollen legs, itching
C49: Man, 41 years	[E, BM] Mud, swamps (w/mosquitoes), worms, animals	Mud	
C55: Woman, 53 years	[B, E] Eating sugar/sweet things, mud, rice fields		
C57: Woman, 51 years, trad healer	[E, B, H] Mud, rice fields, poor hygiene, working hard, poor nerves	Transmissible disease	Swollen legs
NC26: Man, 25 years, labourer	[E, S] Mud in rice fields, black magic	Not human to human	Itching, legs swell, can be sores
NC28: Woman, 50 years	[D] Doesn't know		Affects legs
NC29: Woman, 17 years, orphaned	[B, E, H] Working in rice fields, mud, ancestors who had LF, Dutch brought disease		Leg itches, turns red and swells
NC34: Man, 40's	[B] Working hard, walking		Itching, then swollen leg
NC/C37: Man, 40's, farmer	[D] Doesn't know, health staff says mosquitoes	Human to human	Leg + arm swells, fever, shivering
C38: Man, 37 years	[D, BM] Not sure, opinion of the doctor it is mosquitoes	Human to human	Heavy leg, infection risk, can't walk, pus, boa besar the same
NC39: Woman, 47 years			
NC43: Man, 28 years	[B, H, E] Eating and drinking, work, get it while you are young, climbing, hereditary, water in the forest	Moves between persons b/c hereditary	
NC50: Man, 57 years, head of primary school	[B, H, E] Eating/drinking, cleanliness, animals, swimming, working, climbing trees, not resting, hereditary	Sleeping next to someone, mosquitoes, moves from sick to healthy persons	Fever, shaking, if sick - cannot sleep alone
NC9: Woman, 20's	[BM, S, H] Mosquitoes, entering someone's forbidden land, hereditary		
NC12: Woman, 20's	[E, B] Wind, poor hygiene, communication		Big leg, abscesses, red spots
NC13: Man, 50's, porter	[BM] Worms in the stomach	Mosquitoes	Kaki gajah, boa besar, enlarged breast
NC16: Man, 23 years, farmer	[D, E] Doesn't know, mud, swamp		Swollen leg
NC22: Man, 38 years, civil servant	[E, BM] Mud and swamps (w/mosquitoes)	Doesn't know	Swollen legs, breast, genitals, arms, itches
NC23: Woman, 41 years			Swollen leg
NC24: Woman, 24 years	[E] From Mainang, swamp, mud	Water	Swelling of the leg, affects genitals
NC48: Woman, 30 years	[E, BM] Swamps, water around water tank, mud, worms, mosquitoes		
NC51: Man, 57 years, teacher	[D] Doesn't know		
NC52: Woman, 53 years	[BM, E, H] Mosquitoes in the mountains, mud, hereditary	Human to human	Swollen leg
	[E, BM] Rice fields, worms, mosquitoes, mud		

\*E=Environmental; BM=Biomedical; S=Supernatural; H=Hereditary and/or inherent susceptibility; B=Behaviour-related; D=Don't know // (shaded boxes refer to LF endemic areas)

### **5.2.2. LAY PERCEPTIONS RELATING TO TRANSMISSION**

Prior to this research, in my previous work on Alor, I observed a frequent exchange in the use of the terms cause and transmission. Many respondents of the KAPB surveys I had conducted in the past had used the two terms interchangeably. (Krentel et al. 2006) In the research reported on here, I tried to encourage participants to differentiate between cause and transmission. For questions concerning transmission, I asked how LF was spread (specifically how do you get it), whilst for those concerning cause, I asked what its source was.

The majority of people who knew the disease could pass between individuals knew that it was transmitted by mosquitoes (table 7). About half of the respondents believed LF was transmitted from human to human. In fact, eleven people stated specifically that mosquitoes were responsible for the human to human transmission of LF.

The responses of some participants suggested the prevalence of myths that LF was contagious and could be transmitted through social contact (C54). A few participants believed the disease could be transmitted by sharing soap (C53); by shaking hands or through saliva (NC9) and by walking in the steps trodden by infected persons (NC23). Interestingly, some of these same reasons were given at the beginning of the HIV/AIDS epidemic, when people believed kissing, handshakes and sharing household items like soap and dinner plates would put them at risk for HIV infection. As a result, there was a movement to change that thinking in order to improve prevention efforts and to reduce the discrimination that people with HIV and AIDS felt. For lymphatic filariasis, despite the visual component of the disease (e.g. lymphoedema and elephantiasis), discrimination seems less prevalent and less severe in endemic communities than was seen in some areas with HIV/AIDS.

### **5.2.3. PROGRESSION OF DISEASE**

One of the questions I asked dealt with respondents' perception of the nature of the progression of disease. My intention was to grasp how much they knew and

understood about the long term chronic manifestations of the disease as well as to see if they knew about the symptoms occurring during an acute phase of adenolymphangitis. As might be expected, respondents living in endemic areas offered more information about the nature of the disease than those living in LF-free areas. These people would have encountered neighbours and family members living with the chronic manifestations throughout their lifetimes and would have most likely heard stories about the condition and onset of disease. In my own experience, when visiting endemic villages for *B. timori*<sup>31</sup> in particular, people in the village would tell me about the man with *kaki gajah* on the hill, or their neighbour with the infection and offer to take me to their homes. One woman I interviewed (NC39) actually listed the names for me of the people in her village with hydrocele!

Besides living in endemic areas and having firsthand experience of the disease, some people reported having seen the LF film which the district health team brought with them in advance of the MDA. As a result, they would have seen images of all the different chronic manifestations of the disease as well as the acute symptoms. There would probably have been a short explanation of the disease by the doctor, midwife or district health staff following the film. Other people talked about seeing images at the health centre or in brochures. Information from these sources would inform people, contributing to their knowledge and understanding about the nature of disease.

Compared with those living in endemic areas, those living in non-endemic areas offered less in terms of their description of the disease. Since it is unlikely that they would have had daily contact with people infected with LF, their information about the disease would have to come from other sources. Some of the respondents mentioned seeing people in the market with the illness, seeing the video, seeing pictures and hearing about the disease from people talking about it from other villages. Many of the responses about nature of disease simply listed

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<sup>31</sup> The chronic manifestations of timorian filariasis include lymphoedema of the leg from the knee downwards to the ankle or the arm. Chronic manifestations of bancroftian filariasis include hydrocele, lymphoedema of the breast as well as lymphoedema of the whole leg.



“swollen leg, enlarged breast or swollen genitals.” Some people however, were able to offer more information:

- Man, 48 years old, 4 children, civil servant, non-endemic area (C5): *“The leg gets big and there are always sores. If we see him walking in the market, he is ashamed in front of other people. He feels inferior because people see that he has a big leg. Before there was not treatment to prevent, but now there are not so many people like this anymore, only older people.”*
- Woman, 20’s, housewife, 1 child, breastfeeding, non-endemic area (NC9): *“There is a big leg, abscesses and red spots. When the leg gets bigger, then it will spread. You can’t do anything for it when it is already big. They call it “kaki gajah” at this point.”*
- Man, 23 years, farmer, 1 child, secondary school educated, non-endemic area (NC16): *“There are swollen legs, breast, genitals and arms. It starts with itching that goes on for a long time which makes the leg get bigger.”*

These people are able to offer more information than others living in non-endemic areas as they had access to more information. The man (NC16) saw the LF film; the woman (NC9) came from another more developed region of Indonesia where she learned about LF on the news and; the man (C5) living in Kalabahi is a civil servant and so is likely to have had more access to information in general about health and LF.

In endemic areas, descriptions of the nature of disease were more detailed and specific to the particular form of LF endemic in their area. Below are some of the responses from people living in *Brugia timori* endemic areas:

- Man, farmer, 28 years, 1 child (C20): *“If one person with the disease enters the mud and then a second person enters the mud to work, then he will start to have the disease – itching until the leg gets bigger. When it is already big and there is itching and scratching, and then he gets a fever. Two to three days later, the fever is gone. Three months later, the fever*

*comes again. By then the leg is already big. There are sometimes some small red spots. You have to see the disease with a tool (e.g. a microscope). For those without any symptoms, when you look at the blood, you will see that you don't have any disease in your blood. We can see the small worms in the blood."*

- Man, 30 years, 4 children (C21): *"You are seriously sick if you have LF, if you have a relapse; you have a high fever and cannot go far from the fire. You can't eat or drink until the heat goes away. It itches first, then we scratch it, it itches even more, but if we scratch it really hard, then it swells and we already have it."*
- Man, 25 years, labourer, no children, not finished high school (NC26): *"The symptoms start after walking in swamp mud a long time, then it itches, they scratch and the legs swell. LF has the same symptoms whether it is caused by magic or mud. Caused by mud, there are sores and caused by magic, only swelling."*
- Man, 41 years, farmer, 4 children, junior high school (C30): *"Symptoms are fever, itchy leg, itching and sores form. Then the leg swells. It is hard to treat at this point."*
- Man, 57 years, head teacher of a primary school, 4 children (NC50): *"There is shaking and fever and someone who is sick cannot sleep alone and needs to have someone with him."*

It is interesting to note how detailed these accounts are: the acute form of LF marked by a high fever as well as itching associated with secondary infections in lymphoedema of the leg. All five participants live in areas where the most marked chronic manifestation of the disease is lymphoedema of the leg; so it is likely that they are not aware of the other forms of LF which cause hydrocele or lymphoedema of the breast. Even if they have seen images of these conditions in a film or brochure, it is likely that they would describe the condition most known to them (*B. timori*). Those who were living in areas where there was *W. bancrofti* infection were located quite close to one village (Mausemong) where there were cases of both kinds of LF. Their responses reveal a higher knowledge of both types of chronic manifestations.

- Woman, housewife, 28 years, 2 children (C35): *“There is fever and swelling in the groin. The body is not comfortable and there is scratching. The stomach swells and the intestines (“shiny stomach”) from the liver come out and then the testicles become big.”*
- Man, farmer, 6 children (2 died) (NC/C37): *“The leg and arm swells and then gets bigger. There is shivering, fever, hotness, and then they have swelling. Sometimes it goes away and sometimes it doesn’t.”*
- Man, 37 years, primary school educated, 4 children, head of the neighbourhood, farmer (C38): *“People with kaki gajah can’t walk anymore. And boa besar blocks normal living. According to the doctor, there is shivering every day. Kaki gajah makes walking difficult – walking far, the leg is heavy, there is a risk of infection, water comes out – boa besar is like that too. They can’t leave the village.”*

From these examples, it is clear that people in this area are more aware of two kinds of LF and some respondents were able to mention the symptoms of both conditions. If the hydrocele is small then it is possible to keep it a secret from the rest of the community. On the contrary, lymphoedema or elephantiasis of the leg or arm is more difficult and impractical to hide from view. One of the ways people in the village know that someone suffers from hydrocele is the change in their clothing. One woman (C42) talked about a man in her village who wore a skirt (because of the hydrocele) and as a result, they did not know the severity of his condition. He went to Kalabahi for an operation and came back wearing pants – so in her opinion, his condition had improved.

Additional comments about the long term prognosis for the condition included: “there is no way to prevent it” (NC29); “it is hard to treat at this point” (C30); “it cannot heal” (C14); “you can’t do anything for it when the leg is already big” (NC9). These comments seem fatalistic as each describes an inability either to treat or to prevent disease. There is a certain degree of truth to their statements however; elephantiasis of the leg, once severe, can only be clinically managed to prevent further swelling and present swelling can only be reduced minimally.

### **5.3. BELIEFS ABOUT TREATMENT**

To elicit responses about beliefs about the treatment, I asked a series of questions about the drug itself: its benefits, drawbacks, what happens if you do not comply and what happens if others around you do not comply. In analysing these responses, I explore how these respondents perceived the drug's efficacy and its necessity.

#### **5.3.1. DRUG'S BENEFIT**

Benefits were seen in terms of characteristics of recipients, types of benefit, and properties of the drug. In general, compliers reported more benefits of the LF drug than non-compliers. To this effect, it is important to add that one woman non-complier (NC9) was unable to comply due to breastfeeding. Two of the other non-compliers living in endemic areas suggested that sick people needed the drug most. Compliers tended to list the full range of benefits of the treatment regardless of the endemicity of their areas. Furthermore, several people made specific reference to benefits for future generations (C19; C30), possibly a direct reference from the posters and film we produced which stated that complying now will prevent disease in future generations, specifically for those children born at the start of the MDA.

Respondents reported that there were certain people who benefited most from taking LF treatment. Specifically, they mentioned the individual, the community as a whole, specific people in the community who were particularly at risk, symptomatic individuals, family, children and men. Table 8 outlines their comments briefly; with categories of the most frequent responses listed in the right column (and endemic areas are shaded):

**Table 8 Respondents' comments on who benefits from the LF drugs**

ID number	Individual demographics	Comments on who benefits from the LF drugs	Category*
C4	Female, Apui, 20's pastor	For own personal self. For community to prevent the spread of LF.	S, C
C5	Man, Kalabahi, 48 years	Farmers, get most benefit, then civil servants and drivers.	C
C10	Man, Ampera, 38 years, fisherman	Men benefit most, since 90% of those who have it are men.	M
C15	Woman, Mebung, 38 years	Helps people with a swollen leg because they get better.	LF
C19	Man, Tominuku, 30 years, farmer	Reduction in symptoms; benefit because it helps us to overcome our disease so our children and grandchildren are protected.	LF, F
C20	Man, Tominuku, 28 years, farmer	Drugs are for us, the people. Drug surmounts LF which in is our bodies.	S
C30	Man, Fanating, 41 years, farmer	Effective for LF – young generation will not know about LF.	F
C49	Man, Kalabahi, 41 years	Will be most effective / beneficial for those who have the disease.	LF
C55	Woman, Kalabahi, 53 years	All of us benefit because drugs are good for us and out health. If we have LF inside, it has to come out when we take the pills.	C, LF
C57	Woman, Kalabahi, 51 years, traditional healer	Personal benefit.	S
NC9	Woman, Ampera, 20's, breastfeeding	For all of us individually, for our children, for our family.	S, F
NC16	Man, Mebung, 23 years, farmer	We were sick – now we are well. Benefit mostly for community, 1 <sup>st</sup> the individual, then the family, then community.	C, S, F
NC34	Man, Maritaing, 40's	Drugs work and you need them if you are sick	LF
NC50	Man, Maukuru, 57 years, head teacher	Most beneficial for those who are sick and for those who do not have the disease.	LF

\*S=Self; C=Community; F=family; M=Men; LF=People symptomatic with LF

Fifteen respondents also made references to prevention and cure as a benefit of LF treatment. Although many did not specify how the drug prevented LF, several, offered more detailed information:

- Woman, 20's, 2 children, non-endemic area (NC12): *"It prevents different chronic aspects of the disease, so we need to take it five times – we have one more year to go."*
- Man, 35 years, 3 children, private business, non-endemic area (C14): *"It is an advantage now that people feel they can avoid LF, even though no one*

*has LF, all the people accept the treatment. So once a year, all the people are happy."*

- Man, 23 years, 1 child, farmer, non-endemic area (NC16): *"It's better to anticipate so that our family never gets the disease, and so that we can be together, even though our life is miserable [difficult], the treatment will really help us."*
- Woman, 25 years, no children, endemic area (C53): *"The medication is important for us so that the disease doesn't come to us."*

Three of these four people lived in non-endemic areas and mentioned the importance of prevention of disease. The district health staff in these areas tended to inform people that the drug was primarily to prevent the disease, whereas in the endemic areas, people were more likely to be told it had a combined prevention and treatment benefit.

With regards to cure, some people mentioned their own experience in taking the treatment and reported having felt better afterwards. These personal anecdotes interestingly come from both the endemic and non-endemic areas. Because Albendazole has a strong anti-helminth component, it is likely that many of the positive reactions were related to the elimination of intestinal helminths after taking the medication. The education campaign highlighted this positive side effect of the LF treatment but it was not the primary message. It was nevertheless reflected in comments.

- Man, 30 years, 2 children, farmer, endemic area (C19): *"People have seen a reduction in their symptoms."*
- Man, 28 years, 1 child, farmer, endemic area (C20): *"The drug is good because it surmounts the disease which is in our bodies."*
- Woman, 41 years, 5 children, non-endemic area (NC23): *"My mother who upon taking the pills, she went to the toilet and she expelled what was like a mosquito breeding area in her stomach [lots of small worms]. When she was finished going to the toilet, she had expelled a worm's nest. Before taking the medication, her anus itched...she was pale, she didn't have a*

*desire to work and she was often sitting down...as soon as she took the medication, one week later, her face was beaming and she was healthy again. She is around 80 or 90 years old... I praise God for this so that that my mother can be strong and healthy."*

- Man, 41 years, 4 children, farmer, endemic area (C30): *"The benefit of this drug is that it is effective, it can adapt to the filariasis that is here."*
- Woman, 53 years, 6 children (1 died), non-endemic area (NC52 – although previously a complier): *"The first time I took it, I had no feeling [e.g. side effects]. Before I took it, I didn't feel well after eating, then I took the medication and I felt better after eating."*
- Woman, 53 years, 2 children, non-endemic area (C55): *"The medication is good for us and for our health. If we have LF inside, it has to come out if we take the medication."*

The three people coming from endemic areas (C30; C19; C20) expressed the benefit of the drug more specifically to LF by stating that the drug adapts to LF in the area, by reducing symptoms and overcoming disease. Conversely, those in the non-endemic areas seemed to tell stories about the expulsion of helminths (NC23) or for a potential cure if they have LF inside their bodies (C55).

Several respondents (C15; NC39; NC50) reported themselves or others having felt better or more energised after taking the treatment. One woman from Mausemong (NC39) reported that after taking the drugs one was able to work at anything. The man from Maukuru (NC50) echoed this sentiment recounting accounts where others who took the medication and felt they had a 'heavy body' beforehand, could now subsequently return to work. It is noteworthy that these two respondents, despite having reported the drug's benefits did not take the medication themselves. Finally there were some participants (all compliers: C10; C20; C30) who described the free provision of the drug as a benefit.

Several people knew of no benefits of the drug or reported there being none (C15; NC24; NC26). One man from Fanating (an endemic area) knew there must be good things about the treatment since health centre staff came and gave this



treatment to the people; but in his opinion, the treatment was not good because there were side effects.

### 5.3.2. DRAWBACK OF THE DRUG

“Drawbacks” was translated into Bahasa Indonesia as “*rugi*” which can mean to suffer a financial loss or to lose out. After discussion with my research assistant, this was considered the most appropriate word to use. Table 9 outlines the primary responses of the reported drawbacks. Participants listed two main drawbacks to the LF drug – side effects and the drug’s inability to cure *kaki gajah*. One man (NC26) highlighted the perceived impotence of the drug in the face of magic-induced disease. Mention was also made of the high number of pills risking overdose (NC9). Another man (NC16) said that if people living in endemic areas did not receive the drug then it would be a drawback.

**Table 9 Respondents' comments on the drawbacks of the LF drug<sup>^</sup>**

ID number	Individual demographics	Comments on drawback of drug	Code*
C20	Man, 28 years, farmer	Some people don't see any effect in their sickness after taking the drugs. They don't improve and are still sick, even in the leg.	KG
C30	Man, 41 years, farmer and community leader	The treatment has a hard time killing the worms and healing KG. The researchers have to keep taking blood. I don't understand the point of the treatment, there has been treatment since the 80's and there is no change.	KG
C53	Woman, 25 years	For those with big legs, no change to the leg after several treatment courses; maybe the drug isn't effective for KG.	KG
NC12	Woman, 20's, CHW	Not good because of the side effects: dizziness, nausea, vomiting.	SE
NC22	Man, 38 years, civil servant	I saw my children take the drugs and go straight to sleep while people with LF are still walking around.	SE
NC24	Woman, 24 years	In the villages where people took the drugs, they told the people that all diseases would be cured with these drugs. But no. After taking it, there was itching, so people are afraid to take it.	SE, KG
NC26	Man, 25 years, labourer	No benefit. There is no change after taking it for people with LF. Also I am not sure if the drug will treat magic-induced disease.	KG
NC/C37	Man, farmer	For those who have taken the drugs, there is no change. The medication is only for prevention or to keep the condition from getting worse.	KG
NC43	Man, 28 years	For those of use with <i>boa besar</i> (hydrocele) there is no way that we would be cured by this drug. The drug and the disease are new. We are still natural so we don't want to take the drugs. They don't cure you and you still need to have a massage first.	KG

\*SE=side effects; KG=does not affect the disease (either *kaki gajah* or *boa besar*)

<sup>^</sup>Shaded fields indicate LF endemic areas



By contrast to compliers' comments made in relation to benefits in Table 8, non-compliers listed more drawbacks for the drug. Although side effects were a factor, the major drawback reported was the perceived inability of the drug to work on healing the chronic manifestations of the disease (hydrocele, lymphoedema or elephantiasis). These lay observations are scientifically correct. If someone has severe advanced manifestations, the drug will do little to improve their existing condition; rather the individual will be advised to clean and elevate the affected limb daily in order to reduce the swelling and prevent further secondary infections (Dreyer et al. 2002). As one of the campaign planners, we did not envision this lack of improvement of the leg to be one of the perceived drawbacks to the LF elimination campaign over the long term. Our efforts were focussed on inviting those people with chronic manifestations to health centres to learn how to care for their legs. Furthermore, since the history of the LF elimination campaign in Indonesia (see Chapter 1, section 1.4.) had been fraught with stories of villagers reacting severely to side effects after LF treatment, the campaign focused much of its efforts on stressing that side effects were not dangerous, rather they were positive signs that the drugs were working. The comparative rarity with which side effects were cited as a drawback may indicate that this message was well understood. In addition, it should be noted that these interviews were conducted after the 4<sup>th</sup> round of the MDA; the more severe side effects would have already been seen in the 1<sup>st</sup> round, when microfilaria rates would have been higher.

## **5.4. SOCIAL NORMS AND COMPLIANCE**

Social norms have been described as:

*"...prescriptions serving as common guidelines for social actions. Human behaviour exhibits certain regularities, which are the product of adherence to common expectations of norms...Since the term refers to social expectations about 'correct' or 'proper' behaviour, norms imply the presence of legitimacy, consent and prescription. While deviation from norms is punished by sanctions, norms are acquired through internalization and socialization"*  
(page 168) (Abercrombie et al. 1988)

Norms govern the conduct and behaviour of the group. I use the term here in relation to the Alorese people I studied.

#### **5.4.1. CONCEPTIONS OF GROUP**

Before exploring social norms, we need first to understand how the group itself is conceptualised by the community. In my interviews, I did not specifically ask respondents to define group; rather in the analysis I observed the language they used to conceptualise the notion of a group as well as their references to groups they belonged to.

Respondents most commonly referred to the group using the word “everyone” or “everybody”: “everyone took the pills”; “everyone had to agree to that”; “everyone who was here in the village”; “everybody took it”. Some clarified the notion of “everyone” with definitions varying from the smallest level of the household to larger populations defined in terms of geography. Households in Alor usually conform to a nuclear family pattern - mother, father and children; but they can also include extended family members living there permanently or temporarily for specific purposes (schooling, financial, illness). In many villages, family members live together in one neighbourhood – thus making a neighbourhood a large kin group in effect. One man said that all the neighbours living around him were the same ethnic group as his family (not his wife’s) and each New Year, they counted the members of the group, noting how many had been added and how many had died. In a more urban setting, a man said that neighbours were part of the family and as a result he knew who complied and who did not. For the wider village area however, he was unaware of people’s compliance status.

Among respondents who defined their group in broader geographical terms was a woman living in a rural village who told me that everyone in Alor Selatan took the LF treatment; Alor Selatan being a sub-district of Alor District. Another person told me that “all people in Alor need to take it” – widening the geographical definition of group. Few people identified with being part of the larger group of Indonesians. The Alorese look quite different from the majority of Indonesians

(more like Aboriginal peoples than Malay peoples) and are primarily Christian, differing from the larger Muslim majority in Indonesia. Moreover the eastern part of Indonesia, in which Alor is located, is one of the poorest regions of Indonesia, in marked contrast to the more developed areas of Java and Bali. Furthermore, Alor is in a remote part of an already remote province. During rainy seasons when planes and ships are sometimes unable to travel, it is not uncommon for the islands to become cut off from the provincial capital in Kupang. It is therefore not surprising that the Alorese identify less with being Indonesian than with being Alorese.

Defining social group by area of residence permitted a focus on risk for LF infection. One man remarked that since everyone lives in the same area, mosquitoes will transmit LF anywhere (i.e. everyone is at risk). This concept of group accommodates the notion that if everyone fails to comply with treatment, all risk having LF in the village. As one man noted (NC13) *“the reason everyone must take it is so that everyone is protected from LF.”* Implicit in this notion is the idea of herd immunity, whereby everyone has to comply in order to protect everyone else. A man from a highly endemic village (C19) said that it would be better if everyone in Alor took the medication so that Alor would not become a filarial area. Such comments emphasize not the individual benefit of compliance but the benefit of the group. Sometimes definitions of group included a wider allusion to health care and to mutual aid. For example one man (NC16) referred to the fact that when one neighbour is sick, everyone will take him to the hospital.

#### **5.4.2. WHAT ARE THE DOMINANT SOCIAL NORMS?**

A powerful social norm in the Alorese population is that of conformity, in general, individuals do not deviate from the practices of the majority. The views of those I interviewed confirmed that conformity was an important social norm. A civil servant from Kalabahi (NC22) vividly described the power of the majority in the context of alcohol consumption:

*If this environment drinks alcohol, then the influence of this environment on me is fairly high. Even without mobilising, maybe after some time I will be influenced, it is better that I am together*

[with them].... *The influence of the environment is high enough and will influence the thinking of someone.*<sup>32</sup>

He goes on to say, “*maybe so that he is not alienated, maybe he drinks too, he drinks a little so that he is not alienated for that [not drinking].*” The word for alienated in Bahasa Indonesia is *diasingkan* which contains the root word *asing*, meaning foreign and its use in this context conveys the strength of rejection for not following the larger majority.

In the context of MDA, clearly conformity can be a valuable aid to achieving compliance, provided that is, that the majority favours taking the drug. A farmer from Tominuku (C20) explained the powerful influence of the group when in relation to compliance. Note that Tominuku had one of the highest prevalence rates for LF in Alor and in the past, has had varied success with compliance. The year I did the interviews (2005) was the best year for compliance since the MDA began (2002). He explained to me how the group can influence individual compliance:

*In 100 people, 75 people say to take the drugs, then the 25 who didn't have already lost, because the larger group took it. But if the 75 people don't want to take it, then the 25 are forced to follow them. You have to follow the larger group [and do] whatever they do. If 75 don't want to take it, then 25 won't take it. There is less influence to take it... The larger group influences the smaller group. If 75 want to take it, then they will eventually influence everyone. The small group cannot be strong alone.*<sup>33</sup>

In the case of Tominuku, there was one neighbourhood in which people consistently refused to comply, but in 2005, they were convinced to comply, thus giving the village good overall results. This man was from this neighbourhood.

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<sup>32</sup> “*Kalau lingkungan ini minum alcohol, bagi saya pengaruh lingkungan cukup tinggi. Hanya tidak dimobilisasi, mungkin lama-lama saya terpengaruh, lebih baik saya bersama-sama, mungkin anak dan orangtua kumpul sama-sama di sekolah untuk minum. Pengaruh lingkungan cukup besar dan mempengaruhi pikiran seseorang.*”

<sup>33</sup> I have paraphrased this from the Bahasa Indonesia, rather than a word for word translation, due to the conversational way in which the information was transmitted.

The norm of conformity is a strong influence on an individual's behaviour and choices. People want to be accepted and included and will act accordingly. Social norms related to conformity appeared to support compliance. Participants told me that "everyone must take it", or that "everyone had followed it [e.g. MDA]" or that "you must participate". It is possible that respondents repeated the messages they heard throughout the campaign – that everyone had to take the drug. For many living in endemic areas, however, adherence was not a blind urge to follow the pack; some participants were aware that by complying they would be protecting themselves and their families from infection. This was expressed by several people living in areas where either *B. timori* or *W. bancrofti* were present. One 30 year old man from Tominuku (with two children) (C19) explained that *"the treatment is good so that our children and grandchildren do not get the disease."* Another man, from a nearby village (C21), whose own father had suffered from LF, said that it is best to get treatment so that parents would not have LF or pass it onto their children. One village community leader in Fanating (C30) explained that the best way to convince people in his village to comply with treatment was to tell them that they would be protecting their lineage. This was a message which was repeated throughout the MDA campaign, that taking the medication now would protect future generations from LF, particularly those children born at the start of the campaign.

The second dominant social norm related to the concept of responsibility. Individuals felt that they had an obligation to protect their community and that they had a responsibility to make government programmes work. The Indonesian government remains the main provider of services and employment and one of the strongest influences on the lives of its people. This is nowhere more apparent than in places like Alor, where the government maintains its authority through a history of gifts, sanctions and punishment. Most Alorese would give anything to become a civil servant to ensure a salary and pension for the rest of their lives. It should also be noted that the present *Bupati* or Regent of Alor, is one of the first Alorese to be appointed to this post (previous Regents were sent by the central government in Jakarta). He was vocal at the beginning of the MDA and participated in a

widely publicised film about the disease, treatment and the need for compliance. People are proud of Regent Ans Takelapeda and in general support his initiatives.

This norm of responsibility to the group is echoed in the Indonesian practice of *gotong royong*, defined by Theodore Friend as “mutual help; as in villages cooperating to build a mosque or other project” (page 600) or as a simplified concept of “all for one and one for all” (page 31) (Friend 2003). Presidents Sukarno and Suharto capitalised on this concept while in power; encouraging Indonesians to work together for a common good (Friend 2003). At the village level, this can be seen in the construction of houses of worship or the clearing of land for a football pitch. There is some concern that this principle of traditional mutual help is losing its power in Indonesia as a strong social norm due to increased migration to cities and rapid population growth (Friend 2003).

Presently in Alor where there is less urban migration and moderate population growth, responsibility to the group as a member remains an important social norm. The premium placed on personal and social responsibility was reflected in the comments from a fisherman from Ampera (C10):

*If there is a neighbour who does not take the drugs,  
then we will give him a good explanation in order to  
persuade him how he should take the treatment  
because we see that this one disease is not good. So if  
he doesn't drink, we will direct or persuade him so  
that he will also take it so that this government  
programme will have results in 2010.*

Comments made suggest that people felt responsibility to the wider group. One man (C49), describing the drawings explained that if the woman did not comply and became sick she would burden both her family and her neighbours. He said that when one person is unable to work together with the community, everyone else's work is more difficult. Within a group, there would be pressure not to be the one person who held everyone up because of non-compliance with treatment. Discussing the drawings, a man from Maritaing (C40) told me the non-complier

would be ridiculed because she had refused to accept an effective government programme.

In addition to these social norms, a strong social valuation of health emerged from my data, both economic and social. In economic terms, respondents (C5; C10; NC52) saw accepting the treatment as a way of preventing LF and so avoiding unaffordable treatments in the future. People also recognised that being sick with LF meant not being able to work in the fields (C21; C49). C49, an educated man from Kalabahi, added that if you have LF, then it is a heavy burden on your family. A man from Welai Selatan (C21) recounted his own father's experience with LF, saying that he was sick 3-4 days at a time, during which time the mother and the children had to search for food and make a living. Finally, some respondents remarked how taking the treatment meant that you would be cured and could now work again (C20; NC50). Accepting treatment allowed people to be healthy and therefore be able to work and provide for their families and; this economic benefit was coupled with the prevention of costly payments related to LF disease.

With regard to the social value of health, a civil servant from Kalabahi (C5) told me that if he feels healthy, it means he can have normal relationships with his neighbours, whereas if he was sick, he would feel inferior. If he is healthy he can talk safely, feel prosperous and can interact with healthy people. This same man told me of a man with elephantiasis who came to the local market and seemed shy and embarrassed because of his "big leg". Because LF manifests itself in a visual disfigurement of the limbs or genitals, hiding the condition in more advanced stages is nearly impossible.

### **5.4.3. BELONGING TO THE GROUP**

Being included in the group was important to people and this had implications for compliance. A 25 year old woman from Fanating (C53) told me that if no one else wanted to take it, then she would not have wanted to take it herself, but if everyone wants to take it, then so will she. There is a feeling of safety in being part of the larger group.

To further explore feelings respondents had about being part of a group and the link with compliance; I examined preferences respondents had in terms of a hypothetical neighbour. Using the pictures showing a woman complying with treatment and another, a woman refusing to do so, I asked respondents who they would prefer to have living next door to them. Table 10 summarises their responses:

**Table 10 Respondents' choice of hypothetical neighbour (according to compliance or non-compliance with LF treatment)**

	Chose the woman with the <u>same</u> behaviour as them to be their neighbour	Chose woman with <u>different</u> behaviour to them to be their neighbour	Chose <u>both</u> women to be their neighbour	No choice given
<b>Complier</b>	C4, C6, C10, C15, C20, C21, C25, C35, C38, C40, C41, C42, C49, C53, C54, C55 (16)	C5 (1)	C30, C36 (2)	C57 (1)
<b>True non-complier (by choice)</b>	NC24 (1)	NC16, NC22, NC28, NC43, NC50, NC51, NC52 (7)	NC26 (1)	NC34, NC48 (2)
<b>Situational non-complier (breastfeeding, pregnant, out of village)</b>		NC9, NC12, NC13, NC23, NC/C37, NC39 (6)		

Table 10 shows the strength of the urge of individuals to be part of a larger group and to follow social norms, including those of compliance. Both compliers and non-compliers want to have compliers as their neighbours. Even the sole complier who chose to live next to a non-complier (C5) chose her as a neighbour so that he could go over to her house and impress upon her the need to take the medication. His spirit would not be comfortable and he said he would be disappointed if she then got the disease. He added “*if she dies then we, as neighbours, are responsible for her death.*” One man (NC22), a non-complier, chose a complier as a neighbour so that he could be influenced by them to comply.



The situational (breastfeeding, out of village at the time of MDA) non-compliers also uniformly wanted to live next to people whose behaviours conformed with the social norms.

#### **5.4.4. EVIDENCE OF THOSE WHO DO NOT ADHERE TO SOCIAL NORMS RELATED TO COMPLIANCE WITH MDA**

Despite the strong social norms prevalent in comments by most respondents, there are those who prefer to assume their own risks for LF and make their own individual choices. A porter from Dulolong (NC13) told me that if he refused the medication and was attacked by the disease, it would be his risk alone. A woman from Fanating (C54), where the prevalence of LF is high, told me that everyone is responsible for themselves, that if people did not want to come to MDA, that was their own responsibility. One woman (C57) was *“not sure if her neighbours have taken it or not - I haven't had a chance to ask them. I am busy with my own household affairs. It is up to everyone to decide whether or not they take the medication - if they think it is important to protect they will and if they say, there is no disease here, why bother? It is up to each person – there is no influence.”*

Although social norms are reflected in this sample, there were also those who claimed not to be influenced by these norms and who complied because it was their own choice. There were also respondents who refused the social norms by choosing not to take the drug.

I have described here those individuals who did not comply with the social norm of compliance; however there was also anecdotal evidence from some villages where the social norm was non-compliance and people who did not comply would have been following the prevailing social norm. In some villages near Mainang where the UI-Berhnard Nocht Institute conducted their field work on *B. timori*, there were stories of whole villages and neighbourhoods who refused to comply with treatment. Reasons for their non-compliance were attributed to “provacateurs” who spread rumours about the treatment and the use of night blood taken for diagnosis. Although I did not study these communities in depth, it seems that the concept of social norm of non-compliance could also be as powerful as

the social norm of compliance. It is an area which requires further research to determine if the mechanisms are the same for non-compliance as for compliance.

#### **5.4.5. HARNESSING SOCIAL NORMS AND VALUES FOR COMPLIANCE**

An important feature of the MDA is the public way in which the distribution was carried out and the creation of what is in effect, a social occasion. In most instances, the MDA was a public affair announced by the local health staff, local government or local stakeholders (religious or cultural leaders). Several people explained to me how “busy” (*rame-rame*) the day was – with everyone in the village present at the local health post or how the MDA was announced over a loudspeaker or in the church. One woman in Maritaing (C35) told of how they used this day to take photographs for their health insurance card, ensuring that all villagers would come to the local *kader’s* (community health worker) house for the LF drug as well. A fisherman from Ampera (C10), told me “*everyone who was here in the village today when there to pick up this drug.*” In Welai Selatan, one man (C21) said he knew that everyone complied because there was a list of names from which each was called to come forward and collect the drug. The man from Kalabahi (C6), previously head of the LF control programme at the district level, told me that he knew his neighbours took the drugs because he saw them. He went on to say that they were probably thinking of him which was why they took it. The public context of drug distribution increases possibilities for social surveillance and observational learning and so creates an ideal setting for reinforcing compliance.

In some MDA settings, the health staff prepared boiled water and the people were instructed to take the medication directly in front of them. Operationally, this seemed an effective way of ensuring that people actually took the treatment. A teacher from Maukuru (NC50) said that when introducing something new in the community, people have to see an example, and be given an explanation, before accepting it. If people do not fully understand, then there is the risk that some will sit in the back saying “don’t take it” to those around them. Another man (NC22), a self-declared *tokoh masyarakat* or cultural/community leader, told me that simply

hearing, is not enough to influence people; they need to see action for themselves. In other cases, the drug was collected in public but actually swallowing it would be a private affair. A man from Ampera (C10) reported taking it in front of the health staff and later making sure members of his household who were not present at the MDA received the drugs.

In addition to the visual element of a public MDA, there was evidence that people heard about and discussed the MDA. One 38 year old woman from Mebung (C15) said that *“there was no real gossip about the treatment, but we heard that everyone in the sub-district was getting the pills.”* A man from Maritaing (C40) remarked that he and his neighbours had discussed the treatment and concluded that it was everyone’s individual responsibility to take it. These kinds of communication reinforced decisions to comply. For the most part, the common belief was that the drugs were effective in preventing LF or in curing the disease. This information, initially disseminated by the health staff, stakeholders and *kaders*, was later reinforced by the people themselves. Those who were unsure about taking the treatment were able to go to others they trusted to ask about the pills and whether or not, or how, they should take them. A 28 year old housewife from Maritaing (C35), who had attended the MDA in her village, approached her neighbours for an explanation on how to take the pills – whether to take them one at a time or all at once. A woman from Maritaing (C41) who was unable to attend the MDA but received the drugs when the *kader* came to her household, went to her neighbours for reassurance about taking the pills. She says, *“I had the opportunity to ask my neighbours because the medication was big and small<sup>34</sup> and there was too much of it, and I was afraid to take them, so I asked my neighbours. They said that they had taken them all.”*

The emphasis on conformity and belonging to the group made social reputation an important consideration. A number of respondents (C5; C19; C25; NC/C37; NC39; C40; C49; C57) mentioned aspects of reputation in relation to their motivation to comply. One man (C5) remarked how he would feel if his leg got

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<sup>34</sup> Diethylcarbamazine is a small green pill, of which an adult would have to take three of them. The second drug, Albendazole is a larger white pill, and only one pill is required for an adult. All four pills should be taken simultaneously.

big and how he had to go to the office wearing a tight fitting shoe. Another (NC/C37) said that he would be ashamed in front of his friends if he got LF. These men make a connection between having an infected leg, feeling ashamed and exclusion from the group.

Community health workers and health staff were able to capitalise on the concept of maintaining personal reputation in motivating people to comply with treatment. One farmer (C19) described the community health worker going from house to house and reporting who had taken the pills and who had not. A farmer (C25) described the likely reaction of health staff if they had to treat someone who had gotten LF after the MDA. He said that they would scold the person telling him or her that maybe they had the disease because they did not take the treatment. He added that people in the community would also comment if he became sick that he had not complied with the treatment. This same farmer (C25) remarked that if the community complies with treatment then people will report that Alor is happy and healthy and that there is no disease here because people took their treatment. He speaks here of a wider reputation for Alor which exceeds the boundaries of the village or sub-district whereas the other references to reputation tend to relate to interpersonal relationships within a household, neighbourhood and community.

## **5.5. SOCIAL POSITION AND COMPLIANCE**

A cluster of themes arose from analysis related to a person's place in the social hierarchy. Of particular interest is how social position might influence compliance with LF treatment; within Alorese social life, social hierarchies are evident at the household, neighbourhood, village and government levels.<sup>35</sup> Before exploring these themes, I provide an overview of the strength of hierarchy within Alorese society.

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<sup>35</sup> This section addresses how social position outside of the household might affect compliance, while in section 5.6; I describe how gender affects the power dynamic within the household and its potential influence on compliance.

### 5.5.1. SCENE SETTING

Within the Indonesian government during Suharto's New Order, public administration was designed so that a similar hierarchy present at the central level of government extended down to the smallest villages (Warwick 1986). Despite changes to this structure with decentralisation at the beginning of this century, for the most part the hierarchy remains intact. In the village political structure, for example, the head of the village (*kepala desa*) is at the top of the hierarchy, followed by the secretary of the village (a vice-head of village) (*sekretaris desa*). From there each of the largest division of neighbourhoods, or quarters, has a head (*kepala RW*).<sup>36</sup> The village is then further divided into smaller divisions of clusters of households, with their own head (*kepala RT*).<sup>37</sup> This hierarchy plays an important role in administrative and judicial issues in the village. The size of the village does not determine the existence of these divisions; even the smallest villages have hierarchical official village government structures. The wives of these leaders mirror this same hierarchy in the *PKK* (*Pendidikan Kesejahteraan Keluarga*) which is a programme to educate women on the welfare and prosperity of the family.

The social hierarchy at the village level affected my ability as a researcher to gain access to a community for fieldwork. Before carrying out any interviews, I had first to meet the head of the village and/or the head of the local health centre in order to explain my presence and the purpose of my research. I carried with me a letter from the head of the district health authority, which superseded the power of the village leader and the local health centre. With that letter, I communicated that I had agreement from a "higher power" in the system for my research and by nature of that, it was permissible to comply with my request. Although this was a courtesy to the villages where I was working, it would have been impossible for me to work without the letter and the agreement of the village leader or the head of the local health centre.

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<sup>36</sup> *Rukun Warga*: the administrative unit at the next-to-lowest level in city, consisting of several RTs. (amended from Ahli Bahasa dictionary)

<sup>37</sup> *Rukun Tetangga*: a neighbourhood association, the lowest administrative unit in a village or city. (amended from Ahli Bahasa dictionary)

These hierarchical divisions also exist within other social structures in Alor – in the education systems, religious groups as well as in the household. The criteria governing who occupies positions of power include: age, special roles as cultural leaders, heads of ethnic or tribal groups, position within the family (as head of the household) and religious power or experience. Each individual will be part of many different hierarchies during the course of his lifetime – household, village, place of worship, profession. On several occasions during my fieldwork in Alor, I found myself in the position of leader (of my research team) and so responsible for the safety and welfare of my team. Unlike in the West, mine was the final and only decision for the team, despite my frequent requests for input and advice from my research assistants. On one occasion, we were trying to reach a remote village to do a cluster of interviews. The road to this village was slowly disappearing into the grass and finally we found ourselves on a narrow road which teetered on top of a ridge, with a 200+ feet drop on either side. As we continued slowly along the ridge, the team and I grew increasingly frightened. The driver, not wanting to let me down, attempted to inch along this ridge, in order to pick up the road on the other side. Finally, I realised that we were continuing because I, as the leader, had not said anything. At that point, to the relief of everyone in the car, I announced that we needed to stop and that one cluster of interviews was not worth the lives of 5 people! This kind of situation has occurred many times during my years working on Alor. As a visiting foreign researcher working with the government, my position is higher in the cultural hierarchy than many and as a result, I have learned to be cautious in my decisions once I realised my team would literally follow me off a cliff if I asked them too.

While Alor is a traditional patrilineal agricultural society, the prevalent power relations are fairly universal. Individuals with higher education, increased wealth, or exposure to an urban environment tended to have a higher position in the social system and as a result more power. They were inclined to be more knowledgeable and more able to express their criticisms of the government or the LF campaign. Their elevated positions and the power associated with those positions were described by the individuals themselves as well as by those considered to be at a lower level in the system. I first identify the individuals who were considered to

have authority within the system and how they use that power to motivate compliance; then I discuss how those at different levels of society perceive their own positions.

## **5.5.2. THE ROLE OF PERSONAL POWER AND HIERARCHY IN ACHIEVING COMPLIANCE**

### **Head of the village**

Within the village government system, the head of the village (*kepala desa*) occupies the highest position in this social structure. His or her<sup>38</sup> involvement in the MDA signals agreement and support of the programme and in many of the villages, involvement in the MDA was demonstrated either by publicly speaking about it or by allowing the distribution to take place in the village office. In Dulolong, a seafront Muslim town close to Kalabahi, the head of the village told everyone to come to the village office where the MDA would be conducted (reported by NC13). He would then know who attended and who did not attend. In another village, Welai Selatan, where German and Indonesian research teams have worked in the past, one man (C21) told me that the head of the neighbourhoods gave out names of each village resident to the research teams to ensure that each person collaborated. Not everyone was motivated by the participation of the head of the village: one man (C40) said knowing that the head of the village complied had no bearing on his own actions to comply.

### **Civil servants and community cultural leaders**

Like the head of the village, civil servants and community cultural leaders (*tokoh masyarakat*) retain their power because of their positions within the government and society. In addition, civil servants usually have a higher education level on the whole than the general population. Because of their positions, these people are able to criticize, as well as support the MDA. A civil servant in Kalabahi (NC22) was particularly critical of the government campaign to eliminate LF. He disapproved of the community health worker who came to his house to distribute the medication, claiming that she was too poorly educated to be credible (he

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<sup>38</sup> Although the majority of *kepala desa* are male, there are a few villages in the province with a female head of village.

himself was educated at a Javanese university). He had also witnessed his children's side effects after taking the medication at school and these increased his scepticism of the programme. He recommended that the government use a different mechanism for distributing information about the treatment and disease. He would believe the message more, he said, if he saw it on television or through the INFOCOM (the Regent's information bureau at the district level). Because of this man's position within the government, he was freer to criticise another governmental programme. In addition, his education level placed him above many people working within the district health authority<sup>39</sup>.

A *tokoh masyarakat* or community leader from Fanating (C30) also expressed scepticism about the treatment, claiming that those who took the medication were not cured afterwards (i.e. their lymphoedema did not go away). Fanating is a highly endemic area in Alor in which sufficient compliance in the total population has been difficult to achieve. According to him, government staff would never be able to motivate people to comply and the only way to do it was to use leaders from within the community. One of the reasons he believed people were reluctant to comply related to the trauma they faced in 1965 when President Suharto forcibly eliminated the Communist Party from Indonesia. As a result, people in his community will believe only people familiar to them, and not outsiders:

*Yes, these are common people, people who don't understand. They are still rooted in the traditions here and they have people they believe more than others, because many have suffered trauma from [outsiders], lots of trauma. If someone comes with a free distribution, they [community] ask me if they are associated with PKI [Indonesian Community Party]. PKI gave free goods, and in the end we have family who died as a result, they were murdered.*

As a community leader, this man saw himself as more knowledgeable than his community and the health authorities and less hidebound by traditions. As a result

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<sup>39</sup> When I worked with the District Health Authority at the time of the MDA in 2002, there was only one person at the district level who had a university degree (S2 in Indonesian education system), excluding the doctors and head of the health authority who had a higher level of education.



of this knowledge and his position, he suggested that he might be able to assist the health authority with the MDA.

### **Religious figures**

Religion in Alor is divided between Muslim and Christian (Catholic and Protestant) faiths. Within the village structure, the local priest, pastor or imam will have an important role as an authority figure. During the MDA preparations, we encouraged the use of these religious figures in advertising and promoting the MDA. Through them, we were able to reach the highest numbers of community members as most people came in from the fields for Friday mosque or Sunday church services. Some of these religious figures added a moral component to the MDA during their weekly announcements adding a compelling influence on compliance. For example, in Ampera, a Muslim village close to Kalabahi, a housewife (NC9) told me that the imam announced that it was a religious duty or obligation to comply. She used the word *diwajibkan* which has undertones of Muslim religious pious obligation. A man from Tominuku (C19), a mountainous Christian village, said that the religious authorities (both the Catholic and Protestant) told them that those who took the treatment would be blessed and then announced where and when the treatment would be distributed. In both instances, compliance was linked with religious benefit.

### **Doctors**

Doctors maintain an elevated position within Alorese society because they are highly educated and knowledgeable about health, and so can be important authority figures in motivating compliance and encouraging general health matters. Historically there have been considerable difficulties in recruiting doctors to work in the primary health care centres in Alor. Due to difficult terrain, remote locations in the district and a reputation of conflictive nature in the mountain people, many doctors refuse to be posted in Alor. Many who do agree remain only in the capital, travelling occasionally to their *Puskesmas* (primary health care centres) for clinic days. When I first came to Alor in 2002, the district government had started to recruit young doctors from the more developed parts of Indonesia (Java, Sumatra, Sulawesi). These doctors had just completed their training and

needed to give two years' service back to the Indonesian government. Working in Alor would fulfil that obligation. Communities welcomed these young doctors and the district government hoped that they would stay on past their end of service date. With this new influx of doctors, a total of 13 doctors were working in Alor in 2002.

In Indonesia, most consultations with doctors tend to be a one-sided conversation – where the doctor asks a series of questions to which the patient quietly responds. Unlike many western consultations where patients access the Internet and other scientific literature and are therefore able to challenge their doctors giving input to their treatment plans, Alorese people (and much of eastern Indonesia similarly) accept the diagnosis and treatment without question. In view of this, it is not surprising that community members mentioned doctors as authority figures influencing their decisions to comply.

For example, one man (NC43) I interviewed in Maritaing was a serial non-complier and he told me he tried to influence others not to comply with treatment. When I asked who he needed to hear information from to change his mind, he told me the doctor. Another man (C25) told me that people waited for the treatment once the doctor told them they had to take it. A woman from Mausemong (NC39) said that they believed the doctors because they bring medicine.

As noted above (see section 5.2.1. “Skepticism and lack of knowledge”), doctor's opinions about the aetiology of the disease were met with scepticism by several respondents. In the light of that scepticism and people's respect for doctor's orders in this section, it appears that the doctor does not have to give information; he needs merely to tell people to comply. The evidence is that these respondents value authority derived from status rather than knowledge.

### **Teachers**

School teachers have power at the village level since they represent government staff. Teachers in Alor hold an important role in the community. Once hired by the government, they are employed for life. Corporal punishment and rote learning

are regular features in Alorese classrooms and children learn to respect not challenge their authority.

In most villages in Alor, staff from the local health centres went to the elementary schools (in many villages that is the only school present) and distributed the medication there, having the children take the pills immediately in the presence of their teachers and health staff who were present. During my fieldwork, we visited an elementary school where the MDA was being carried out. The children sat quietly while their teacher called their names out. One by one, the children came forward to accept the pill from the one of the numerous health staff at the front of the room. Out of the 40 children present, only one little boy was exempted from compliance; he was terribly frightened and cried when his name was called. The teacher allowed him not to participate. The other children, however, all complied with the treatment when their names were called.

Parents in general were not aware of the MDA at their children's school. They were neither asked for consent nor given information about the drugs and the possible side effects. One mother (C15) said that she was unable to say anything about her children taking the medication at school. Another (NC23) told how she felt badly for her children's side effects. Rather than directing her concerns to her children's teacher, she rebuked her children for not asking their teacher if they could take the treatment home with them and take it after lunch. One father (a civil servant) (NC22) was concerned about the side effects his children had; and said that as a result he would not comply and risk side effects.

These examples suggest that, from a young age, acceptance of the social structure and authority is inculcated in Alorese people through the school system. This early process of internalization<sup>40</sup> of the social norm of respect for authority is seen in the children's ready acceptance of the pills as well their parents' general unwillingness to challenge the idea of treatment-taking without their consent.

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<sup>40</sup> Internalization is defined as "the process by which an individual learns and accepts as binding the social values and norms of conduct relevant to his or her social group or wider society." (page 127) Abercrombie, N., S. Hill and B. S. Turner (1988). Dictionary of Sociology. London, Penguin Books.

They may not have liked the treatment and the side effects their children suffered may have even frightened them, but not one of the parents I interviewed mentioned anything about protesting to the school. They demonstrated their unwavering acceptance of the authority of the school system and health system in matters relating to their children's health.

### **Outsiders to the village**

Respondents also talked about people coming from outside the village who influenced their decisions, from the district government and from international organisations. When district health staff comes to a rural village, they usually create quite a stir – coming in a car and often with a team of people. This in its own right draws people to a location, particularly when rural. Additionally, because of the hierarchy in the Indonesian system, a visit by someone from a higher echelon can also be an event. These people may be coming to supervise or advise; and so are perceived to be more knowledgeable as well as more powerful. One man from Fanating (NC26) described how they came in with the ambulance using the village public announcement (PA) system to call everyone to come and get the medication. He told me it was busy (*rame-rame*) and that the head of the village was there too, explaining to everybody what was happening and encouraging everyone to take it altogether. I asked this man why everybody complied, and he answered that “*from [the authorities], they said it was for filaria, so they took it.*”<sup>41</sup>

Several of the respondents mentioned the involvement of international institutions or individuals in the MDA. Their impact was perceived as either frightening or modern and advanced. Two men (C20; C21) from the Mainang region where the international research teams had been working mentioned their involvement. One (C20) said that the Germans had come to Alor to overcome LF. They told him that he had LF and gave him medication for it. Another (C21) from a nearby village in the region said that teams from Germany and Switzerland had come to work on LF in his village. In fact there were no Swiss people involved in the project, only Germans and Indonesians from Jakarta (who may have been almost as foreign as

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<sup>41</sup> “*Memang dari sana bilang ini untuk filaria, akhirnya mereka minum.*”

the Germans in such a village).

It is not surprising that these two men would remember the involvement of these foreigners in LF work. The researchers usually came and stayed in the area for a couple of weeks in order to take blood samples at night. Many of the people living there would have come into contact with them either for the research or in day to day living. Another man (C30) living in a village quite far from the Mainang area told me that the drugs had come from the World Health Organisation. He is most likely repeating what the health staff told him when they came for the MDA. A farmer from Mebung (C25) explained what foreign drugs mean for his community: *“these drugs are not made by us here, people from outside the country made them. They came here for us, the people of Alor.”*<sup>42</sup> An older man living in Maukuru (NC50), a rural coastal village where LF is highly endemic recalled the impact of the visitors on his own actions. An American missionary pastor told him that when he was sick, he should take traditional medicine and since then, he had followed his advice.

These statements demonstrate perceptions of foreign involvement in LF elimination as good; sometimes even better than that offered by Indonesians. This may be a longstanding belief in Alor; but it has been augmented within the last few years with the influx of foreign NGOs who responded to an earthquake and a measles outbreak on Alor in 2004. Otherwise, foreign aid on Alor is limited primarily to church-related clinics and the German government (GTZ), which has been well reputed in the district for the last ten years or so. These foreign bodies, although outside of the traditional social hierarchy, nevertheless occupy an elevated position in their inherent association with modernity and the West. This status can be used to influence compliance.

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<sup>42</sup> *Ini obat bukan kuta yang buat sini, orang dari luar Negara sana yang buat datang jadi untuk kita masyarakat di Alor ini orang tidak tahu tapi itu sebenarnya supaya oh...saya punya orang di sana sehat-sehat.*

### 5.5.3. HOW IS AUTHORITY USED TO MOTIVATE COMPLIANCE WITH LF TREATMENT?

I spoke with one community leader (C30), we talked about the kind of information that people in his village needed before they complied with treatment:

Interviewer: *So what would you say [to someone who did not comply]?*

Respondent: *First of all, old people don't know Bahasa Indonesia, they only know their local language, so we must first have a good explanation, saying that this medicine needs to be taken, if Bapak [Sir] wants to ensure that he has good descendants. If Bapak doesn't want to take it, then it means that Bapak will have descendants who will not continue/advance. Bapak, you have an inheritance/legacy, because soon enough all the legs will be like this [lymphoedema]. If we say that, he will start to think "oh". Because people here have traditions, the culture of descendants is the most important, so if we speak like this, it is clear he will take it.*

Interviewer: *Ok, so it's like that. And we don't need to given any information about mosquitoes and...*

Respondent: *Ah, there is no need. The principle is to give a second for that sort of thing, because if we talk about filaria, he doesn't understand.*

In this dialogue, the community leader revealed his perception of the people below him in the social hierarchy: people rooted in tradition, who may not understand explanations about the transmission of disease. In his opinion, the only message to use to reach his community should tap into local beliefs and appeal to their emotions; that is taking the treatment to ensure the healthy continuation of the family line. This may not be a rational statement as the inverse is not true (that all descendants will be disabled in the case of non-compliance); however he believed this emotional appeal to be more successful than a more rational biomedical explanation. By communicating with his community at this level, he inadvertently maintained his position of increased knowledge over the community by withholding more scientific information from them.

I conducted a couple of interviews in villages near Mainang, an area which is part of the University of Indonesia and Bernhard Nocht Institute research project on the use of DEC and Albendazole. Each year a team of Indonesian and German researchers comes to these villages, takes night blood and gives LF treatment. During the course of the research, there has been a history of dissent in nearby villages caused by provocateurs challenging village leaders' authority, in relation to the LF campaign, much to the confusion and dismay of the research teams. Three men from this area (C19; C20; C21) revealed that people were afraid that the government was selling their blood at the outset of the research project. One (C21) believed they were selling it to people with anaemia. These comments were a direct result of rumours pervading the area at the time the research teams began in 2002. As the civil servant in Kalabahi (NC22) told me less educated people in the villages base their decisions on rumours, rather than logic. These men demonstrate how members of the community might be swayed by those spreading misinformation in order to destabilise a leader.

Another important concept which emerged was people's need to see an example or have a role model, before they accept something new. When the MDA was designed in Alor, health centres were encouraged to develop a village-specific approach for drug distribution together with the authority figures in the village. By tapping into this existing hierarchy it was hoped that people would be motivated by following the example set by their authority figures. Remarks to this effect were made by four different people who were all leaders or persons in authority in their villages: a teacher, head of the neighbourhood, a pastor in the church and the husband of a community health worker. The teacher (NC50) from a rural endemic village explained that people who did not fully understand the implications of compliance for prevention and cure of LF needed to see their friends take the pills first, and to see that they suffered no ill effects. For new things, he added, people must see an example (though for himself, he needed no such example because he already understood why compliance was important). The head of a neighbourhood in Mausemong (C38) explained to me that *"I recently took it, because as a boss I take it, doing it so that the community [or the people] know that all of this is a*

*government programme which is good.*"<sup>43</sup> The pastor (C4) told me that she would be able to influence others to take the treatment in her church. The husband of the community health worker (C14) also explained that if his wife had not taken it first, then the community would be afraid and would not want to take it. He adds that *"we must take it first so that it will draw them in to motivate them to take it."*<sup>44</sup> These four individuals (NC50; C38; C4; C14) from their own positions of authority are able to describe the importance of their status in convincing the community to comply with treatment. Leading by example, they can show people that the medication is safe and government sanctioned.

#### **5.5.4. EXPERIENCES OF THOSE IN RECEIPT OF AUTHORITY**

The majority of people I interviewed held little power within their community. Many were farmers and housewives with only an elementary education. Their comments relating to authority often revealed deference to those above them in the social hierarchy. They cited reasons relating to a lack of knowledge, power or funds. For ease of analysis, I grouped these themes together and have described them in terms of a "serf mentality". The Cambridge University Press dictionary defines a serf as "a member of a low social class in medieval times who worked on the land and was the property of the person who owned that land." The word "serf" captures the concept of powerlessness and passive acceptance of a higher authority. It suggests that a person's subordinate status makes him unable or unwilling to challenge authority. Within this research, displaying a "serf mentality" would imply that someone accepted without question the treatment or that they were unable to refuse compliance. This concept is expressed in Bahasa Indonesia as *nrima* or passive acceptance (Friend 2003). Cora DuBois discussed similar connotations in her book on the Social Forces in Southeast Asia, drawing out the difference between feudal systems in Europe and in Southeast Asia:

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<sup>43</sup> "Kalau baru-baru saya sah saya minum, karena sebagai pemimpin itu minum, lakukan supaya masyarakat tahu bahwa semua itu adalah program pemerintah itu baik."

<sup>44</sup> (for whole segment) "Artinya paling pertama adalah mereka kan masuk kader Filaria kebiasaan masyarakat didesa itu kalau kader tidak minum kan membuat masyarakat merasa panik takut begitu dorang sendiri tidak minum masa dorang minta kita yang mau minum jadi kita yang harus minum duluan itu untuk bagaimana bisa dapat menarik mereka begitu untuk memotifasi mereka untuk minum"



I shall not use the term feudalism in discussing Southeast Asian society. There is to my mind a vast difference between the European lord and his land-bound serfs on the one hand and the magico-religious god-king symbolizing a world order in Southeast Asia. In Southeast Asia, but certainly not in Europe, the wealth and the sexual potency of the ruler, the splendour of the court and the temples were projected and sublimated expressions of cultural well-being. The lords seem to have been less the masters of serfs and more an expression of the peasantry's greatness. The state was not the exclusive, aggressive structure of European nationalism but was rather the symbol of a world order, and the expression of a system of proprieties in human and superhuman relationships. (page 31) (DuBois 1967)

Elements of this description continue to pervade Alorese society today. I know of one village leader who was rumoured to be powerful because of his knowledge and abilities in black magic. He had at least 13 wives that people knew of. The historical roots of kings (*rajas*) in Alor remain evident in today's society, both in the rural and urban areas. For example, the GTZ guesthouse in Kalabahi was owned by a member of a powerful king's family; ensuring the house's security despite its location in the centre of town near to the port. These kings do not necessarily hold government positions; but they retain power and influence in Alor and have wealth to support their position.

While it is clear that Indonesians today are not slaves and own their own land, aspects of the serf mentality remain, perhaps due to the slow transition from the feudal system to a more modern society. Historically, slavery existed throughout Indonesia, including Alor, and remnants persist today in many Alorese villages. The oldest clan (*suku sulung*) are the traditional land owners and all other clans in the village are considered to be later arrivals. In some cases the later arriving clans originated from slaves bought from Malay slave traders. These clans were the formal possessions of the oldest clan in the village. Today, in some areas of Alor, members of these slave clans are more outward looking and are becoming the new elite, creating tension with the oldest clan in the village. (Personal communication with Dr. František Kratochvíl)

This serf mentality was also perpetuated by official government, in particular during Suharto's presidency. In relation to health, Suharto showed a significant indifference to the health of his people, particularly the poorest. "By treating the peasant consciousness politically as a "floating mass," he incidentally ensured that there would be no village-organized health lobbies. Peasants were to be fed and taught, with the implicit assumption that the hardy would endure" (page 146) (Friend 2003) Suharto lost power in 1998 and the government has made significant attempts to reverse many of the decisions and policies which were enacted during his long tenure in power. Although elements of this transition are present (the more outward looking slave clans and the decentralisation of power), remnants of the serf mentality continue to exist.

Evidence of this mentality was found in my data. Some respondents stated explicitly where they lay in the social hierarchy of their village. Specifically, two male farmers (NC16; NC40) used the terms "little" people (*masyarakat kecil*) or "common or non-expert" people (*masyarakat awam*) to describe their own communities – the first in response to a question about the Indonesian government and the latter in the context of people's perception of side effects. One of the farmers (NC16) further described himself in the interview as an example of the "littlest" person:

*In my opinion, who knows what the capability of Indonesia is to surmount (or overcome) [LF] or not. We don't know – we are little people here so if they give us services, then we accept it; if not, then we sit quietly like this. That is the arrangement from the people who organise this area, for example from the district, to the province, all the way to the national level. They have their management – they know more about the situation in this country, how to advance this country. They know how far the capability is. We, the little people, don't know. They know.*<sup>45</sup>

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<sup>45</sup> "Menurut saya begini negara Indonesia ini kan entah kemampuan untuk mengatasi seperti ini ada atau tidak kan kita tidak tahu kita ini masyarakat kecil jadi kalau dilayani kita terima kalau tidak dilayani kita duduk diam begitu jadi itulah itu urusan dari orang-orang yang mengatur ini wilayah macam dikabupaten propinsi sampai kenegara itu mereka punya urusan mereka yang lebih tahu bagaimana kan keadaan Negara tu kelebihan maju mundurnya Negara itu kan mereka yang tahu kemampuan sampai sejauh mana kan kita masyarakat kecil begini tidak tahu mereka yang tahu."

In these comments, this man explains how “little people” do not know about the working mechanisms of government at any level. His responsibility as one of them is merely to sit and wait for services to be brought to him; and if the government does not provide them, it must be because they deem it unnecessary. These statements reveal a sense of ignorance and passivity with regards to interaction with government. He trusts that the government knows more than he does. A fisherman (C10), expressed it differently. Asked about people who refused treatment, he replied: *“if rich people who already have a deluxe car and a good house still think about our health, and we the people, if we aren’t concerned about our own health, then we are mistaken.”*<sup>46</sup> This man was impressed by the fact that wealthier people were concerned about the situation in his rural village. He owned neither a car nor a fancy house, and so placed himself in a lesser position than those who did, accepting that they knew more about health.

The idea of a “serf mentality” has connotations which can be seen as an antithesis to development and modernity. This last respondent was impressed by the concern of wealthier people from outside of his village. Another man (C19) from the mountains of Alor expressed the same concept of his own subordination, and that of his community, in relation to others from outside. He told me about rumours generated by his community during the first round of MDA in his village Mainang. One of the rumours claimed that the research teams were taking the people’s blood and selling it. After some time, they realised how ridiculous this idea was that the researchers would want sell their “dirty blood” (*darah kotor*) to other countries. The concept of dirty blood in eastern Indonesian culture means that you have a disease which needs to be removed<sup>47</sup>. This man concedes that his community has blood unworthy for use in other locations.

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<sup>46</sup> “...orang yang kaya sudah punya mobil mewah punya rumahnya sudah bagus tapi masih memikirkan kita punya kesehatan kita masyarakat tapi kalau kita juga yang tidak mempedulikan kesehatan kita ya memang kita sudah terlalu keliru saya menyatakan disana begitu.”

<sup>47</sup> Other related concepts of dirty blood: when women menstruate, they get rid of dirty blood in their bodies. If they don’t menstruate, then the dirty blood accumulates and must be taken out. Dirty blood can also refer to conditions associated with sexually transmitted infections, abscesses, itchy and swollen skin. These conditions can also be associated with curses, particularly for unhealed disease. (Personal communication with Heny Nggadas)

Another characteristic of a “serf mentality” is freedom from having to think for oneself. This concept of blind faith is present in many interviews, as I have highlighted in the following statements:

- A high school educated man (C14) whose wife is a community health worker responding to the question “what if people do not know where the disease comes from; why would they still want to comply?”: *“I already said it, this is a programme from the top, from the health authority and it is required to distribute to the community to take this treatment for free.”*
- A 41 year old woman with 5 children (NC23): *“[the medication came] from the government to the Puskesmas, then from the Puskesmas to the people, and we silently accepted.”* She continued on later in the interview to say that *“if we know the government wants us to be healthy, and they help with the drugs, then whatever the government brings, we must follow whatever it is for our own private health.”*
- A young woman whose husband is a farmer, no children (C53): *“we didn’t ask any questions [we] just accepted the treatment.”*
- A 51 year old woman with 7 children (C57): *“There is no way that this disease is in the city – so there is no need to take it. But then it is better to prevent the possibility. Also there is the government and people there who already know that there are symptoms here – so we take it.”*
- A 53 year old woman with 6 children (NC52): *“We don’t have LF here, but we take it anyway. If they gave us poison, we’d take it. We believe the health authority – we are more afraid of getting sick.”*

This last statement most explicitly states the complete blind faith which is expressed in the above comments. Some people would even take poison if they were given it; such is their belief that government has their best interests in mind!

Another characteristic feature of this subordinate mentality is the powerlessness to refuse the commands of those higher up in the hierarchy. A school teacher (NC50) from a highly endemic region explained that people in his village would not be brave enough not to comply because it was a government decree. Moreover, on

the day that the drugs were distributed, the people in his village could not leave the village. As a school teacher, he would understand how power of the government could influence people.

Asked why she decided to follow the government's LF treatment programme, a woman (C54) living in a highly endemic area replied, "...the government calls...we are the community...we must follow. We cannot oppose the government. [Why not?] ...we are afraid. [Why are you afraid?] We are afraid that if we don't follow, we might get the disease."<sup>48</sup> Because of her social position, her response to a government call or request is to follow it. Her additional motivation is fear of getting the disease. I will discuss in more detail the effect of emotion as a motivator in section 5.8.

In a similar vein, a 51 year old woman (C57) from Kalabahi told of being accustomed to following government orders; they may not not follow (*tidak boleh tidak ikut*) a government recommendation. She gave an example of the family planning programme in Indonesia, which declared that everyone must have between 2 and 3 children. She added that she had more children (7 children) than the government prescribed, but that it was permissible since they were farmers. This woman explained how common it is for their community to respond to a government order.<sup>49</sup>

Government in Indonesia is strong as we have seen. While some more developed areas like Java and Bali may experience more open debate with government decrees, in rural less-developed areas, the government still remains an impressive force responsible as sole provider for most of the services people require (health, education, pensions, etc.). People are less likely to refuse the services offered or

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<sup>48</sup> *Karena pemerintah panggil, jadi kita ikut...Namanya kita masyarakat, pemerintah omong, kita harus ikt. Kita tidak bias lawan pemerintah...Kita takut... Kita takut karena jangan sampai penyakit kena kita."*

<sup>49</sup> Her response represents an anomaly. She described the strength of the government's recommendation; however she freely admitted that her status as a farmer allowed her the freedom of nonadherence. Perhaps her reasoning stems from the fact that farmers need more children for the work in the fields.

prescribed, as they have less choice and less bargaining power than more educated people living in other more developed parts of Indonesia.

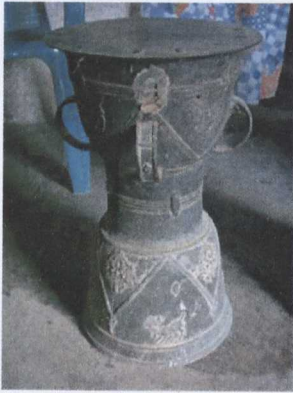
A further theme relates to people's gratitude for the services delivered to them. If one considers oneself as merely a receiver and not a participant, then thankfulness seems logical. Some respondents said how grateful they were to the government for their assistance. One man (NC16) even said that the government "loved" (*cinta*) the people. One woman (NC9), an unofficial community health worker, told me how grateful she was to the doctor for the medication. She talked about how poor her village was and having no access to television or news and how if the disease came, they would not have money to take care of it. However, now they were protected because they had taken preventive medication. The provision of this preventive treatment may save them money in the future.

Another woman in Maritaing (C42) echoes this woman's comments when she says whatever the government gives, they accept with happiness. These are people taking care of the community and help comes by giving money or rice.

## **5.6. GENDER RELATIONS AND COMPLIANCE**

In this section, I examine how the role of gender and social position affect decisions to take the LF treatment under four headings. I examine the general concept of gender and social position in Alor; different models of responsibility for health care decisions in the household; how power is demonstrated and; how gender might affect compliance with LF treatment.

### **5.6.1. SCENE SETTING**



At the household level in Alor, a patriarchal hierarchy exists where the man is the official head of the household. One manifestation of his power is his right to purchase a bride. A bride price is exchanged between the husband and the woman's family. In Alorese culture, a man must purchase his wife using a traditional brass drum called a *moko* (see picture). Within Indonesia, *mokos* are only present on Alor and therefore are unique to Alorese culture. The origin of the *mokos* is unclear, but there is some speculation that they came from Vietnam centuries ago. Depending on the value of the woman, the man must purchase one or more *mokos* to give to her family before the cultural wedding can take place. A *moko* can cost in the region of 1,000,000-3,000,000 Rupiah (70-270 US dollars) and the rarer forms of the *moko*, the *moko pun* (pronounced pūn), have been known to sell for five times this price to overseas collectors. It can take some men many years before they are able to pay for their wife, and as a result, they will live together as common law spouses before being married culturally. The pressure to pay the bride's family can increase with time, causing stress for the couple. They will not be culturally married and independent of the bride's family until this price has been paid.

A female doctor in Maritaing explained the effects of the bride price on marriage relations in Alor. Once a woman is married, she becomes the man's property and as a result becomes like a third class citizen. Alorese men joke about this, saying that they have to beat their moko to make it sound (Personal communication with Dr. František Kratochvíl). Cora DuBois (1944) discussed the effect of the bride price on a woman's right to leave her husband. In the event of the woman wanting to leave, she must first have the support and agreement of the male members of her own family (brothers and father). If they agree to take her back, then they must return the precious *moko(s)* to the woman's husband. Relinquishing this valuable asset is often deemed as foolish and as a result, the woman must remain in her unhappy marriage so that the financial gains of her own birth family remain intact. Today, because of their great value, *mokos* are sometimes used as collateral



for a loan. It is possible go to the largest supplier of loans in Kalabahi and see a warehouse full of *mokos* collecting dust which have been put forward as collateral for loans.

From the above descriptions of the transaction of marriage, it would seem that Alorese women hold little power within their own households. Yet in fact, the power of Alorese women is greater than their status within society might suggest. Their control of the production and preparation of food has long given them power rather than prestige (DuBois 1944). At that time, DuBois described how women were responsible for the majority of the cultivation, fulfilling the role of mother-provider for both their children and their husbands. I have seen this tradition continued today as women carry the primary responsibilities for cultivation and production of food<sup>50</sup>. Moreover, it would not be uncommon nowadays to see, during the day, a husband at home with a baby enwrapped in a colourful *ikat*<sup>51</sup> around his shoulder while his wife was out working in the fields. Since women take a more active role in farming, the men or other family members take over watching young babies in the home.

DuBois described a woman's ambiguous position in marriage:

“... marriage means for women far greater economic responsibilities in a social system that does not grant them status recognition equal to that of men, while at the same time it places on them greater and more monotonous burdens of labour. For women complete adult status through childbearing is not rewarded socially; it is to an extent penalized in that it adds to labour and responsibilities. The important role of women is covertly recognized but not overtly.” (page 114) (DuBois 1944)

Recognition of women's contribution to the household was thus implicit rather than explicit. Men retained the ceremonial role as head of the household and were recognised for that, despite the fact that they contributed significantly less in terms

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<sup>50</sup> Men are primarily responsible for slash and burn techniques used to prepare the fields for the planting.

<sup>51</sup> An *ikat* is a kind of cotton woven and dyed cloth which is part of the culture of NTT province. Each district, and sometimes it is as specific as villages, have their own unique patterns and colours. One of the ways that men carry the babies is to wrap the child in an *ikat* and then around his shoulder, thus freeing his hands.



of work than women do. An Indonesian phrase “*hak tidak wajib*” expresses this concept appropriately, meaning – “rights not obligation”. According to my observations, this is still the case. Men have rights as head of the household and family, but have little obligation to their family in terms of providing for them. Today, in parts of Alorese society, many young women who have become educated refuse to get married because of this situation. (Personal communication with Dr. František Kratochvíl)

Externally, the central government perpetuated the subjugation of women in official policies. Suharto created a national organisation called *Dharma Wanita* (translated as ‘the duty of women’) which put women into the same hierarchical structure as their husbands in the government, civil service or military. Theodore Friend writes:

All were treated as women of Java, wherever they were from, and as wives of their husbands, whatever their independent career or talent..... An openly rebellious woman, or even an impassively noncompliant one, could endanger her standing in the eyes of the regime, jeopardizing her husband’s career and her family’s future.” (page 254) (Friend 2003)

Many Indonesian women have experienced both traditional cultural structures, like the system in Alor, and the official government structures reinforcing their position in deference to their husbands. With the fall of the New Order, organisations like *Dharma Wanita* continue to exist, but have less power and influence. Furthermore, the proliferation of women’s rights and empowerment NGOs and increased education for women have begun to shift women’s positions across Indonesia, albeit at an uneven pace.

### **5.6.2. GENDER AND RESPONSIBILITY**

The evidence from my interviews suggests that Alorese men continue to be perceived as the providers in their roles as head of the household, and this has implications for their perceptions of the importance of maintaining good health. A 48 year old man with 4 children living in Kalabahi (C5), for example, told me that if he was sick and did not take any medication, then he will feel burdened because

he has a wife and children. He added that he must be healthy so that he can get life's necessities for them. He said, "*I am a father, if I am sick, everybody's sick.*"<sup>52</sup> He interpreted his role as head of the household as meaning he is solely responsible for providing for his family. Any illness he may have, in his opinion, would seriously affect his family. He was a civil servant living in the district capital, so it is possible that his wife would not have a field to cultivate, leaving him as the sole earner for the family.<sup>53</sup> Another man, 43 years old with 3 children living in Maritaing (C40) told me that he has to be healthy himself before he can take care of others, like his children, his community, his district and his country. When asked to prioritise people in terms of the importance of taking the treatment, he put himself first, then his wife; ensuring his own health would enable him to ensure the health of his household and his community. These men recognised their roles as chief provider and manager of their households, even expressing as the first man did, the burden of this responsibility when they are unable to fulfil it.

There was also evidence of a man's responsibility for the continuing survival of his family line. A 41 year old farmer from Fanating (C30), for example, suggested that the best way to motivate people in his highly endemic village was to tell the men that they should ensure their lineage is healthy by complying with the treatment. He purports that it is the man's responsibility for his lineage and future generations.

### **5.6.3. PRIORITIES FOR HEALTH CARE PROVISION IN THE HOUSEHOLD**

As the heads of the household in Alor, men are accorded priority for health – often before their wives and children. Interestingly, it was primarily women who told me that men have the highest priority for health. Only one man, a farmer with 7 children (C25), saw both his wife and himself as having the highest priority for health in their household. The women, on the other hand, almost exclusively put their husbands' health above their own. Many of these insights arose out of the

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<sup>52</sup> "*saya seorang bapak kalau saya sakit semua sakit*"

<sup>53</sup> Some families in Kalabahi do have small plots in town where they raise corn or some vegetables.

exercise where respondents arranged statements relating to prevention and cure of LF in terms of community, self, children, district and country in order of priority. Their comments are paraphrased below:

- Woman in her 20's from Ampera, one child (NC9): *"My husband's health is first, then myself, then my children's."*
- 38 year old woman with 6 children from Mebung (C15): *"I choose Indonesia as the first priority; Alor as the second; my husband, other family members and community as the third; my children as fourth; and myself as last."*
- 41 year old woman with 5 children (NC23): *"In the household, the father is the highest because he is the head of the household and responsible for arranging the wife and the children in the household. I consider as most important my husband because he is the head of the household, like I consider Jesus as the most important in my life and my husband is number 2. I have the opinion that I have to look after my husband's health first."*
- 28 year old woman with 2 children (C35): *"Husband is in the number one priority place together with the wife, and then their children come afterwards."*

The response of one woman appeared anomalous in this respect. She was 48 years old, had 6 children (C54) and gave the following priority list for LF treatment: 1. Indonesia; 2. her community; 3. herself; 4. her children; 5. Alor. Asked where she would place her husband, she added, while laughing, in with the people in Alor, last on her list. This woman's background is important to an understanding of her response. Her mother was kidnapped by her father from Ujang Pandang and taken by force to Alor. In the interview, she told me how her mother nearly went mad due to being stolen away from her family and never assimilated into Alorese culture, dying young. I believe that this woman, as a result of her mother's story, also felt outside of Alorese society (she would only be half Alorese) and as a result, she placed her Alorese husband together with the Alorese people last on her list. By putting Indonesia first, she demonstrated where her allegiances were.

#### 5.6.4. DECISION-MAKING IN RELATION TO HEALTH

Four models of responsibility for health decision making emerged from the interviews: in some families responsibility was primarily the husband's; in others it was primarily the wife's; in others, responsibility was shared by both husband and wife; and in yet others, responsibility was autonomously assumed by each individual for his or her own self, regardless of the course of action of the other spouse.

With regard to the first of these, only one man, a father from Maritaing (NC34), said that in the household the father takes the health decisions. He adds that if the father is not there, then the mother will take any decisions in his absence. This man presents the husband as having the prime responsibility for taking health-related decisions and provides a plan for when the man is unable to be present in the home. He does not mention any collaboration between husband and wife in the decision-making when the husband is home.

For the second model, there were many examples of women having prime responsibility for health in the household, which would seem discrepant with the husband's prime role as head of household and main decision maker as seen in the previous section. The fact that women have the main responsibility for health is in keeping with the cultural context of Alor, where the women's duty is to look after the household and its needs. This is illustrated in the account of a 48 year old mother of six children in Fanating (C54):

*I: In your household, can you tell me who is responsible or concerned about health?*

*R: Health is the risk for us, women. [You] are willing to [look after] clothes, [look after] the interior of the house, and also the [look after] back of the house [where the kitchen is located] – it is the responsibility of the woman.*

*I: What about the man?*

*R: The man only knows how to call people to come over.  
[Laughs] Whatever there is, or isn't, it is the responsibility  
of the housewife.*

*I: And if the children are sick?*

*R: Sick children, also, it is I who takes care of them.<sup>54</sup>*

This woman actually jokes that her own husband is able to do little to assist her in the day-to-day running of the household; somehow mocking his claim to be head of the household. Her dialogue shows the difference between formal control (her husband calling people to the house) and informal control (taking care of the kitchen, sick children, laundry, etc.).

Four other women and one man (C53; NC52; C42; NC23; C49; with an average age of 43 years) held that it is the women's responsibility to take care of health in the family:

- Woman, 25 years old (married at 16 years old), husband is a farmer, no children (C53): *"The wife thinks more about health because it is she who prepares the food and drink in the household."*
- Woman, 53 years old, 6 children (NC52): *"The wife is involved and responsible for health in the family."*
- Woman, 55 years old, 7 children (1 died) (C42): *"Who takes decisions for health in the household? The mother. She can disagree with the husband. Children hear their mother usually; the father is just dear to them [sayang saja]."*
- Woman, 41 years old, 5 children (NC23): *"In the household, it is usually the mother who has the responsibility to give the drugs to the husband and the children after they have eaten."*

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<sup>54</sup> R: Kesehatan itu resiko kita, wanita. Maunya mau pakaian, mau dalam rumah, mau sampai belakang, bertanggung jawab perempuan. I: Bapak? R: Bapak hanya tahu panggil orang datang... Ada, tidak ada, bertanggung jawab ibu rumah tangga. I: Kalau anak-anak sakit? R: Anak-anak sakit juga, nanti saya yang urus.

- Man, 41 years, 4 children (C49): *“He is not the boss of health in his household. It is his wife who takes more responsibility for health and reminding them of health.”*

These participants describe the way that women assume responsibility for health matters in their households: taking care of sick children, thinking about health, preparing food and drink, reminding their family members about health, taking decisions for health, instructing their children and giving medication. These are nurturing and caring actions.

The third model, that in which responsibility for decision-making regarding health is shared between men and women, was described in the accounts of 6 participants (NC9; NC16; NC23; C35; NC39; C40 with an average age of 37 years):

- Woman, in her early 20’s, 1 child (NC9): *“Responsibility for health to me is all of ours and even more so in the household. We shouldn’t wait for the husband to say we need to take care of health.”*
- Man, 23 years old, farmer, 1 child (NC16): *“In the household, the husband and wife together are responsible for health.”*
- Woman, 28 years old, 2 children (C35): *“Father together with the mother makes the health-related decisions.”*
- Woman, 47 years old, 4 children (NC39): *“Mother and father take decisions together about the health of their children.”*
- Woman, 51 years old, 7 children (NC23): *“Both husband and wife care about health – it is important.”*
- Man, 43 years old, 3 children (C40): *“Health decisions are sometimes made by himself, sometimes by his wife and sometimes together.”*

Shared responsibility for health reflects a more westernised pattern where both the husband and wife are involved in decision-making in the household, and where there is greater gender equality. Interestingly the average age of those respondents who believed that health decision-making was a joint responsibility

was 37 years old; 5 years younger than those who put the full burden of responsibility only on women (average age of 43 years).

The fourth model of decision-making for health, in which individuals made autonomous decisions regarding treatment, was exemplified in the accounts of respondents who were all from highly endemic villages for LF infection. A 25 year old man from Fanating (NC26) told me how his wife had complied with LF treatment and how he had neither forced her to comply nor prohibited her from doing so. Based on her experiences with side effects, he decided against complying himself. The husband of a 47 year old woman in Fanating (C54) had told her that she had her own fate and it was her own risk whether or not she wanted to comply with the treatment or not. A 28 year old woman in Maritaing (C35) complied with treatment whilst her husband laughed at her attempts to encourage his compliance; she told him the health staff would not give him drugs in the future if he needed them. While a woman with 7 children in Kalabahi (C57) remarked that if the wife wanted to take it and the husband does not, then each one was on his/her own. A 37 year old farmer from Mausemong (C38) remarked how his wife was an adult and she can take it. Finally another man from Mausemong (NC/C37) told me that his wife and children complied, however he did not.

These couples were all discordant in relation to compliance – with the wife taking the drug while the men refused. Interestingly, one woman (C35) reported joint responsibility for health in the earlier section as well as autonomy to comply with treatment here. Some of the men (husband of C35 and NC26) were strongly against compliance; but despite this, they did not interfere with their wives' decisions to take the drugs. By the same token, one man (NC51) reported no pressure from his wife on his own decision, *“my wife wasn't angry with me because I didn't take it.”*

#### **5.6.5. GENDER RELATIONS, POWER AND INFLUENCE**

Participants had a further opportunity to describe the power balance between husband and wife, and its influence on compliance, within a fictional household.

As noted in Chapter 4, they were asked to describe drawings in which a woman was seated at a table with a packet of medication and a glass of water in front of her. In one drawing she was taking the medication, in the second, she was staring at it - immobile. In both, a man stood in the doorway and two children played on the ground in front of her. (Appendix A.6.)

Whether discussing their own real life or the hypothetical situations in the drawings, participants made references to the use of force, or the threat to do so, by men. In accounts of their own lives, both men and women used words like “order”, “have to take it”, “must” or “is not allowed” - usually to describe a man’s command to a woman. These words reveal imperatives rather than persuasion. The previous head of the LF programme (C6), for example, told me that he *ordered* his wife and children to take the treatment. A man from Tominuku (C20) said that the woman in the drawing *must drink* the treatment because it is there to surmount the disease, adding that the man had already drunk the medication so his wife must too to prevent the disease being transmitted to the family. A farmer from Mebung (C25) reported that as he is head of the household, if there was someone in the household who did not want to take the medication, it could not be. It was his responsibility to make sure everyone took the medication.

When explaining what was happening in the pictures, several men (for example, NC16; C19; C25; NC43; C49; NC/C37) described the fictional husband’s right and responsibility, as head of the household, to give orders to his wife to comply or not to comply with the MDA and the husband’s greater knowledge, while women (for example NC9) told of the wife’s inability to refuse her husband’s wishes. In describing the pictures, the respondents painted a strong picture of male supremacy. Again, the language used included imperatives such as ‘must’, and verbs with forceful connotations such ‘order’, but the comments on the hypothetical situation revealed perceptions of a heavier handed approach on the part of men (C25 even interpreted the husband’s intentions being to hit his wife) compared with the accounts people gave from their own experiences.



These portrayals of male supremacy seem to contradict participants' accounts relating to decision-making about health within the household reported above (section 5.6.4.). In response to questions about who made health care decisions in the household, the majority of respondents spoke either of joint responsibility or of some autonomy on the part of husband or wife. Comments from four individuals (NC9; NC16; NC22; C49) illustrate these contradictions particularly strikingly. All four in their real-life accounts talk about joint responsibility for health yet all spoke of force when describing the drawings. One, a woman (NC9) commented in relation to her real life situation "*we should not wait for the husband to say we need to take care of health*", whilst acknowledging the man's authority in the hypothetical example stating that the woman cannot refuse her husband's force. Similarly, the farmer (NC16) expresses his own commitment to joint responsibility but speaks of the fictional husband being able to order his wife to comply because of his responsibility for the household. The university educated man in Kalabahi (C49) had told me that he was not the boss of health in his household, rather that his wife was, and acknowledged that his description of the drawings differed from his description of his own experience; he interpreted the drawings in terms of the woman being forced by her husband to comply, but stalled when I asked what would happen if she refused; he had rarely seen evidence of that and so could not answer.

How can these apparent contradictions be interpreted? It is certainly not the case that women in Alor enjoy the same degree of freedom as their husbands. Curtailment of women's movements by husbands does occur. A 30 year old woman from Kalabahi (NC48) told me her husband did not allow her to go to her neighbours' houses because he was concerned that she might gossip with them. (When I interviewed her, she had only until noon to speak with me because her husband would be coming home for lunch. I ended up cutting the interview short, because her fear was interfering with the interview.) This was also described to me by a European nun who worked in eastern Indonesia for over 35 years. She told me that men fear when their women "*omong terus*" or talk non-stop. Such restrictions may not directly affect compliance with the MDA, but they may have

an indirect influence since discussion with neighbours about the treatment may be beneficial in terms of creating social norms favouring compliance.

The protected status of women and the confinement to the household and to family duties was also, in some cases, a barrier to access to the drugs. One man (NC34) told me that in his house, no one took the treatment because he did not go to get the drugs; his family had no option to comply because there were no pills. A woman from Ampera (NC9) also told of her husband's 'gatekeeping' actions. When picking up the drugs for the family, he told the health staff his wife was breastfeeding and as a result, they did not give him drugs for her. She accepted his decision without question.

At the same time, it seems it is not within men's power or persuasion to control their wives' every movement. A 38 year old with 3 children (NC22), was unsure whether his wife took the treatment, but surmised that she probably had not done so because he was suspicious of her taking the medication in her current pregnant condition. He added that he would not have forced her to comply anyway; he had seen information on women's empowerment on television and that he would not want to be reported for forcing her. He laughed and said that he did not understand enough about it.

These accounts reveal the complexity of gender relations in Alorese society. There seems to be a continuing tension between the old, traditional, patriarchal society and a more modern egalitarian system of social organisation. It is possible that the tendency to describe real life situation as less patriarchal, and the fictional scenario as more so, may reflect a gradual transition from the older to the newer form of social organisation. But it seems also to be the case that elements of the two orders, old and new, exist side by side in contemporary Alorese society. Alorese people are still able to relate to the old system and to describe its norms regarding traditional gender relations; but they are increasingly exposed to a more

modern culture (through television, movies or education<sup>55</sup>) and to begin to modify their own household and thinking according to this newer norm.

## **5.7. THE ROLE OF COERCION IN COMPLIANCE**

In this section, I examine the role of coercion in achieving compliance and so move towards a concept of influence that admits less voluntary action on the part of the individual. The concept of coercion is more akin to force than autonomous decision-making.

As defined by Richard Coker in the context of tuberculosis control in New York City in the 1990's, coercion refers to:

... the act of compelling someone to do something by the use of power, intimidation, or threats. It is a complex concept that covers a wide range of meanings, from the subtle to the overt, from friendly persuasion, to interpersonal pressure, to control of resources, to the use of force. (page 17) (Coker 2000)

Coker's range of meanings is apparent in the data from Alor in the form of threats, moral punishment, intimidation and interpersonal pressure. Coercion can be seen to lie at the extreme end of the same continuum along which power and social position lie. People in power are able to influence others by using coercion, threats and by inflicting punishment.

### **5.7.1. SCENE SETTING**

As discussed earlier, Alor is traditionally hierarchical, and as a result, some forms of coercion might be expected as a way of keeping the social strata defined and in place. Cora DuBois described forced participation in cultural events in her observations of the people in Atimelang, Alor in the 1930's. She observed members of this community coercing their kin to participate in feasts and other ceremonial obligations. Feasts and celebrations are expensive, and obligatory for a variety of reasons – notably the appeasement of ancestors and demonstration of

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<sup>55</sup> Two of the people discussed in this section (NC9; NC16) reported external influences: NC9 lived in Batam, another region of Indonesia before coming to Alor and talked about watching television there during another part of the interview and NC16 told me about learning English in school, watching Western movies and listening to English songs.

social status. DuBois observed kin members being forced to provide the needed pig and participate in a feast. (DuBois 1944) Pigs were and are seen today as symbols of wealth and so are not readily slain or sold; yet in this context, people would have had no choice but to participate in the feast.<sup>56</sup>

Forced participation has long been a feature of Indonesian public health programmes. When the national family planning programme (BKKBN – Badan Koordinasi Keluarga Berencana Nasional) was officially launched in the 1970's, the government purposely used the existing hierarchical structures within village government to promote compliance with family planning. The BKKBN system relied heavily on the active participation of village leaders and their wives, on religious figures, volunteers and health staff. At the start of the programme, the head of the village and his wife were in charge of the contraception distribution centre and had responsibility for creating a climate in which family planning was acceptable and for approaching eligible couples in their village and encouraging their use of contraception. (Warwick 1986) The World Bank's Development Report in 1980 (World Bank, Washington, D.C.) documents the method of implementing family planning at the village system. At monthly village meetings, roll calls began by asking each man to announce what form of birth control he and his wife were using. Once the level of participation in the community reached its target, the village was rewarded by the government with food, health care, water supply or road repairs. The Report (1980) observes that the pressure on non-acceptors would have been terrible; as they would be seen to be holding their community back from necessary development projects.

Throughout the history of the family planning programme, there have been allegations of use of coercion. Warwick (1986) describes evidence of oppressive force in a village in East Java where, in the presence of civilian, police and military leaders, women were taken into a house where IUDs were being inserted. In East Timor, there were reports of women being coerced into using contraception – often by military personnel. Reportedly 62% of all family

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<sup>56</sup> This may also relate to the power the older established clans have over newer clans (see earlier section 5.5.4.). One form of intimidation can be to force them to participate in feasts, such as the account told by DuBois. (Personal communication with Dr. František Kratochvíl)

planning users in East Timor relied on injectable contraceptives; a figure double that of neighbouring Irian Jaya. (Sissons 1997) The struggle for independence from Indonesia significantly influenced government programmes in East Timor; and according to Sissons (1997) family planning was not exempt from being a political instrument in this struggle.

I myself encountered references to the use of force in family planning campaigns in Alor. From a nurse working in Alor, I heard about nurses and midwives entering villages accompanied by military and government officials during the 70's and 80's, forcibly providing contraception. I was told that the health staff was paid for the number of acceptors they got. One woman (C57) recalled that if they did not follow the family programme, it was their own fault (rather than their own choice). Another (NC12) mentioned that family planning workers had been co-opted into the MDA for lymphatic filariasis; perhaps a subtle reminder for the community of past coercive techniques.

Despite allegations of coercion, the Indonesian government has received international acclaim for its achievements in reducing overall fertility. Contraceptive prevalence rates increased markedly at the end of the 20<sup>th</sup> century even during the economic crisis in 1997-8 when there were changes to providers and choices of contraception available (Freedman 1990; Frankenberg et al. 2003; Schoemaker 2005). The family planning programme showed that there can be positive effects of coercion (social or otherwise) on compliance in health programmes. Nevertheless, ethical issues arise with this success (namely does the end justify the means?) and need to be considered in the context of MDA for filariasis in Alor.

What is the relevance of the family planning programme for the LF elimination programme? It establishes the precedent for the use of coercion in public health programmes and demonstrates its effect. Moreover, there are several similarities between the two programmes. Like the family planning programme, the LF elimination programme is a vertical programme directed by central government. Even in the context of decentralisation, district governments must rely on drug

supplies from the national programme. Both programmes have been associated with success – the family planning at national level and Alor at district level. Since Alor was a pilot area for the national programme, achievement was especially important – not only to eliminate the disease and improve development, but to show that a small remote and under-funded district of Alor was able to achieve success in disease control.

The MDA also mirrored the family planning programme in its use of the village government structures and in motivation of elders, religious figures and leaders to support and carry it out. And, as with the family planning initiative, drug distributors were paid a nominal fee for each person who took the treatment.

Similarities between the two programmes also extend to the use of coercion as we will see.

### 5.7.2. COERCION USED BY AUTHORITY FIGURES

Some respondents were people in positions of power and authority and were directly involved with the LF programme. As a result, they were able to describe how they intimidated people by their tone of voice or by their use of personal rebukes. These comments were made by authority figures involved in the distribution in three different communities:

- Community leader in an endemic village (C30): *“I only shouted that everybody must take the medication.”*<sup>57</sup>
- Husband of a community health worker (C14): *“...if someone didn’t want to take the medication, we would force [him]. We would give him the treatment.”*<sup>58</sup>
- Community health worker (NC12)<sup>59</sup>:

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<sup>57</sup> “Saya hanya serukan saja bahwa semua harus minum”.

<sup>58</sup> “...unsur negatif artinya kalau misalnya dia tidak mau minum kita paksa kasih dia minum...”

<sup>59</sup> “I: Rasa apa dengan orang yang menolak minum? R: Jengkel I: Kenapa? R: Karena tidak mau minum obat sedangkan kita yang membagikan kadang ada yang tidak mau ambil tidak datang kadang kita marah ikut kerumah. I: Kalau masuk dirumah bilang apa? R: Marah-marah kalau tidak mau ambil nanti kena penyakit tu kaki gajah bukan hanya kaki gajah saja tapi Filaria tapi apa payudara besar juga untuk wanita untuk yang pria kan yang boa besar kena boa besar. I: Jadi

*R: Sometimes they don't want to take it, or don't come; sometimes we are angry and go to their house.*

*I: If you go into their house, what do you say?*

*R: [We are] really angry if they don't want to take it, soon they will get this elephantiasis disease, but not only elephantiasis, but with filariasis there is big breast for the women and for the men they get hydrocele.*

*I: So you force them, but what if they don't want to take it?*

*R: [They] don't want to take it, then it's a risk.*

*I: So if you enter their house really angry, how do the people answer?*

*R: They are silent [motionless], silent and then straightaway take the medicine.*

The yelling referred to by C30 is clearly intended to intimidate while C14 makes direct reference to the use of force; adding later in his account that force is necessary so people will understand. The woman (NC12) describes the intimidation and public rebuke people suffer if they do not pick up the drug or refuse to take it; their response to which seems to be immediate compliance.

These accounts are reported in an interview and so, it is possible that coercion and intimidation are accepted as common features of everyday life. A local pastor (C4) reported on the intimidating language used by the health workers in her village. Discussing the drawings, I asked her what she would say to the woman who refused the treatment. She answered, “[Speaking] *roughly... with coarse language, we are angry! Like just recently the health staff to those who didn't want [to take the medication] now they will transmit [LF]*<sup>60</sup>.” She imitates the health staff and in so doing, seems to acknowledge intimidation as acceptable behaviour.

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*anda paksa, tapi kalau tidak mau minum bagaimana? R: Tidak mau minum ya resiko. I: Jadi kalau masuk rumah marah-marah orang jawab apa? R: Mereka diam, diam langsung ambil obat”*

<sup>60</sup> “kasarnya, .... bahasa kasar kita marah...! seperti itu baru-baru tenaga medis bagi tidak mau sekarang baru begini terjangkit.”

Several references to the use of enforcement or intimidation by health workers were made when describing the drawings depicting different scenarios involving MDA. A woman (C41) from Maritaing described the scene: *“the health worker orders the woman to take the medication quickly and he or she will be angry and threatening so that for sure she will take it.”* A woman from Kalabahi (NC52) explained that *“the community health worker must force the non-complier in the drawing to take the medication so that she does not get LF.”* A porter from Dulolong (NC13) saw the doctor in the picture guarding (*menjaga*) the non-compliant woman, *“dia komando”* or “he’s commando” and if she continues not to take it, he will be angry. The word *komando* has strong links with the Indonesian military, meaning a command or order as in the military (Personal communication with Heny Nggadas). In the past, there has been a strong association between the civil service and the military. During Suharto’s New Order, Warwick (1986) writes (p 462), “Under the concept of a “dual function” of the armed forces, many military personnel were assigned to civil service positions. Among their tasks, they were asked to help with development program implementation (Smith 1971).” This porter could have been referring to these earlier times when the government was more closely associated with the military.

Others who were associated with the use of coercion included husbands and teachers; two groups to whom reference has been made elsewhere (see section 5.5.2. and 5.6.5. respectively).

### **5.7.3. EXPERIENCES OF COERCION**

In addition to those who reported having used coercion to achieve compliance with treatment, there were also those who had themselves experienced its use. A farmer from Mausemong (NC/C37) described its effect on his behaviour:



*Ever since I was small, I did not like to take medication. But recently I took it because there was force, so I just had to take it. Let alone taking medication or getting an injection, I don't want to.*<sup>61</sup>

Later in the discussion, however, he said he had not complied that year. When there is no force (as perhaps was the case in this particular year), he had not complied with treatment.

A housewife in the eastern part of Alor (C35) reported a similar effect:

*I: ...when you came and saw that your neighbour had already taken it...you saw them directly take the medication, seeing that, what did you think?*

*R: I thought, like this, this drug was taken right away...so indeed it must have been ordered to take it.*<sup>62</sup>

This woman describes her neighbours' response – they complied with the treatment – and she interpreted that they must have been ordered to. She also complied, although she does not mention any force in relation to her own decision.

Similarly, another woman (NC24) from the western part of the island held that if people forced them to take it, then for sure they would comply. She complied the first year, but refused the second because of the side effects experienced by her two children.

A woman in Kalabahi (C57) recalled information received during the MDA: *"You may not throw away these pills. You must take them; to prevent any possibility. So there wasn't anyone who said 'leave these pills behind'. We must take them...Even though there is no disease here, yet we must take it."*<sup>63</sup> She used the

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<sup>61</sup> "Memang saya sejak dari kecil tidak suka minum2 obat. Yang baru saya minum ini karena keadaan terpaksa jadi saya harus minum saja. Jangankan minum obat apalagi disuntik, saya tidak mau."

<sup>62</sup> "I<sub>1</sub>: apa efek waktu ibu datang lihat oh ada tetangga dia sudah minum, ibu sudah, bapak sudah minum, ibu langsung lihat mereka minum, ibu lihat pikir apa? R: saya pikir begini, ini obat apa kok langsung diminum, disuruh minum memang."

<sup>63</sup> "Ini obat tidak boleh buang. Harus minum... memang penyakit ini tidak ada di kami. Tapi harus minum."

phrase ‘must take them’ three times here, in addition to the word “*boleh*” which means ‘be permitted’, so the context of her account, the meaning is ‘not permitted to / may not throw away the pills’. The act is non-negotiable – she must take these pills, even though there is no disease in her area.

Others, however (C5; C14; C54), reported having no experience of the use of force:

- Civil servant living in Kalabahi, male, 48 years old, complier (C5):  
*“...here we are preventing first, which is much better, already I feel happy because there was no force. I understand that this treatment is good for prevention.”*<sup>64</sup>
- Private business, male, 35 years old, complier (C14): *“I see here that if we don’t want to accept [the drug] then there are no sanctions at all. There is no sense we want to refuse; also there is not one demand we must take and drink...”*<sup>65</sup>
- Woman, married, 6 children, complier (C54): *“In my opinion, each has his own risk. You want to go [to the MDA] – you go. Don’t want to – don’t go. There is no force.”*<sup>66</sup>

C5 and C14 imply that there is no force to comply adding their willingness to take the medication anyway. C54’s comments imply that the decision to comply was an autonomous one; she lived in a highly endemic area for LF, so the risk of infection would be significant.

Some respondents felt that the use of force would actually discourage people from complying with treatment. One woman, a community health worker in a suburban community of Kalabahi (NC9), believed that force would not work, that if people

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<sup>64</sup> “...jadi kita mencegah dulu lebih bagus, sudah saya rasa senang sekali tidak ada yang paksa saya mengerti bahwa obat itu bagus untuk pencegahan itu.”

<sup>65</sup> “Kita artinya disini saya lihat itu kalau kita tidak mau terima juga tidak ada dia punya sangsi apa-apa, tidak ada artinya kita mau tolak juga tidak merupakan suatu tuntutan harus kita ambil dan minum tidak inikan bagi masyarakat yang dia merasa supaya besok lusa dia jangan terjadi penyakit artinya kena penyakit seperti itu kita minum, kalau yang tidak tidak pernah dipaksa untuk harus minum itu tidak inikan bantuan artinya pelayanan cuma-cuma dari dinas kesehatan begitu”

<sup>66</sup> “Kalau pendapat saya, resiko masin-masing. Mau pergi – pergi. Tidak – tidak. Tidak memaksa.”

were forced to take the pills then they would not want to do so. A man from Maritaing (C40) confirmed this, claiming that no one was forced to take the treatment and that if they were, he would not want to take it, for sure. Such sentiments were also expressed in discussing the drawings. A woman (C54) in Fanating, describing the man she supposes to be the doctor in the doorway supervising the woman's compliance, spoke of how people tricked the authorities into believing they complied with treatment. Many people she knew hid the medication when asked to take it in front of the health official, drinking water only (*air kosong*) instead of swallowing the medication, which they threw away later. The gist of this woman's comments was that coercion can backfire – people may comply publicly as a response to force, while privately refusing the treatment.

#### **5.7.4. WHAT KIND OF COERCION WAS USED IN THE MDA?**

Types of coercion described in accounts ranged from the overt to the more subtle.

##### **Threats**

As reported by respondents, threats had to do with the condition of the disease as well as the withholding of services in the event of non-compliance. To be effective, people had to believe that the threats would be carried out. A farmer living in a suburban area (NC13), where there was no reported LF described the nature of the threat he had experienced. The head of the village explained that people would get a swollen leg if they did not comply with treatment. For those working in the fields as subsistence farmers, the idea of losing the ability to work would have provided a strong impetus for compliance.<sup>67</sup>

Other evidence about threats came from the health staff themselves. In 2005, I learned from two different health staff at the *Puskesmas* level that they had approached non-compliers and informed them that they had better not be sick in the coming year, because they would be refused treatment at the health centre due to their non-compliance. One nurse went so far as to write down the people's

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<sup>67</sup> This man is a reported non-complier. He had received the drugs within the last day and he and his wife planned to take them that evening. Because he had not yet taken the pills, I have labeled him a non-complier despite his intentions to comply.

names and then report them to the *Puskesmas*. He told me that the people were afraid when he came into the village. He was proud of his behaviour because there was a high compliance rate for that village. Whether or not they would have refused service to a sick individual, I cannot know; what is significant is that the threat was made by two different staff in two different areas suggesting that it was not an isolated behaviour.

It is likely that Indonesians are familiar with the tactics of withholding services. Respondents reported their fear of not getting treatment at a later date if they refused the treatment now. A mother living in suburban Mebung (C15) told me: *“if we wanted to refuse and supposing we got sick, we would go to the health centre and they would say – we’ve already given you the drugs, and you didn’t want to take them, so now you got sick.”* In a similar vein, another mother living in Kalabahi (C57) said that *“it is better that we take the drug now, because maybe the local government leaders will be angry later if we don’t and we get sick. They will say – the doctor has already come and now you’re sick! It’s your own fault! You take your own risks. They will not help you if you get sick, you will go to the hospital alone.”* Both of these accounts illustrate the fears of these women relating to the consequences of non-compliance – the government and health centre would turn their backs on them for their foolish behaviour. It is important to add that in Alor, as in many rural areas in developing countries, you cannot go to the hospital alone. There is no food service, sometimes no bedding and in Alor, you must go to the pharmacy to purchase the materials required for your medical intervention. If you go alone, you cannot take care of these necessities. The threat of no medical assistance could be a strong influencing factor for people with few resources for tertiary medical care.

### **Moral judgement**

There was also evidence of a more subtle kind of coercion. People described the moral punishment they would face from their community if they did not comply with treatment. Remembering the power of social norms and their impact on influencing compliance, we can understand the power that such a threat might have on an individual.

Two people, both community leaders, described for me the impact a non-complier would have on the community. Here is an excerpt from my discussion about the drawings with a community leader (C30) in a highly endemic area:

*I: In your opinion, what will happen to this lady who refuses?<sup>68</sup>*

*R: If indeed she refuses and she doesn't take the medication, then she will be a source for the disease, she will be a source of filaria to transmit to all people who have already taken this medication. . Then if she is a source, she is a container sheltering this disease... if the government is exceedingly stern; she can be fenced in, not allowed to live with family, she would be expelled so that this disease could not breed. If she may take the medication, she may mingle then with the other community members.<sup>69</sup>*

This community leader judged that the non-compliant woman would become a source of LF for the whole community. His proposed control measures have strong parallels with quarantine strategies and refer to the more coercive public health strategy of containment and control, rather than persuasion and social learning. Used in the past during outbreaks of infectious diseases such as AIDS and multi-drug resistant tuberculosis, containment and control strategies have led to debate on the tension between the rights of the individual and the rights of the general population. Containment involves the ultimate use of coercion – detaining someone against their own wishes.

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<sup>68</sup> I: kalau ibu contohnya dia tidak hamil, mungkin dia pikir dan dia tidak mau minum. sedang pikir dan setelah ini dia bilang, saya tidak mau minum. Menurut bapak apakah yang akan terjadi dengan ibu ini yang menolak.

<sup>69</sup> R: kalau seandainya dia menolak dan tidak minum bearti dialah yang sumber penyakit, dia ini yang sumber filaria untuk menularkan ke semua orang yang sudah minum obat ini. Jadi ini dia sumber, dia satu wadah itu untuk penyakit ini berlindung, daripada orang lain. Jadi dia ini sebenarnya kalau pemerintah yang terlalu keras; dia bisa sebenarnya dipagari, tidak boleh dia tinggal dengan keluarga, dia dikucilkan supaya penyakit tidak boleh berkembang. Kalau dia boleh minum obat, dia boleh bercampur saja dengan masyarakat yang lain.

In a similar way, the head of a village in a central area of Alor<sup>70</sup> explained that the government told everyone that they must drink the medication. If they did not, then they would become the cause of the illness for the rest of the village. He seemed to think that this was an acceptable manner of influencing the community to comply.

Both these accounts reveal moral punishment on non-compliers. They are perceived to be the future sources of disease and are responsible for undoing the work done by the MDA in the rest of the community. In areas where LF is present (as was the case in both of these accounts), this kind of judgment might be more severe; considering that people understood the impact the disease can have on working, family and community life. In fact in highly endemic Mausemong (NC/C37), one man told me that if some people do not take the medication, then they should move away. In a similar fashion, when we did the pilot project for the MDA in 2002, one of the midwives we worked with informed me that she told people in her endemic community that if they did not comply with treatment, they should move out of the village, that they were not wanted there anymore.

Village leaders were not alone in their moral judgement of non-compliers; neighbours and families were also seen to express their criticism of people who fell foul of the social norm to comply, as illustrated by this excerpt from a discussion about the drawings with a mother in Maritaing (C41):

*I: And what about the woman who refuses, who didn't take the medication?*

*R: Ya, if she didn't take it, for sure she will get it, the filaria disease just at that moment.*

*I: If the neighbours know that she has the disease right away, what about that?*

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<sup>70</sup> This man was not part of the 43 in depth interviews and so therefore does not have an identifying number. His was the village where the pilot KAP survey was done in 2004 and his comments were made during a visit with him prior to administering the questionnaires.

*R: Ya, for sure they will go and get medication for her to take or they will go to the hospital to get that filaria medicine to give to her to drink.*

*I: They won't be angry with her?*

*R: For sure they will be angry with her first, and then they will go to the hospital to get the medicine for her to drink (laughing)*

*I: So they're angry, what do they say?*

*R: Ya, they're angry saying why when the community health worker was distributing the drugs [you] didn't want to take it? And now [you] already have gotten the disease and now [your] family or neighbours have to come and go search for a doctor to take care of her.<sup>71</sup>*

She finishes the discussion by telling me that the woman will be ashamed (*malu*) by the neighbours' outburst. By not taking care of your own health, you impact those around you by involving them in your medical care. In Alor, one is not sick on their own without impacting on their environment. A university educated man in Kalabahi (C49) explained to me, within the context of the drawings, how the family works in relation to a diseased or sick member:

*In Alor, people have a high value for family [kekeluargaan tinggi]. Therefore, when the woman in the drawing does not comply and gets sick, it is not only her family and household which are affected, but her neighbours will also feel the impact. If she's sick, everyone has to think about helping her. Everyone's burdened. If she doesn't want to take the drug, what can we do? Force? If there is someone who refuses, and they get sick, the neighbours can come and yell and force her to take it.*

Aside from burdening the family and neighbours when one is sick, there is also the notion that people who do not take care of their health and accept free

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<sup>71</sup> "I: dengan yang tolak, yang tidak mau minum? R: ya, kalau dia tidak minum pasti dia akan kena, penyakit filaria begitu. I: kalau tetangga tahu dia langsung punya penyakit bagaimana? R: ya, pasti mereka sudah mencoba minum atau mereka akan ke rumah sakit untuk mencari itu obat filaria untuk mau minum [untuk kasih ke dia] ya. I: mereka tidak marah dengan dia. R: pasti dong marah dia dulu baru mereka ke rumah sakit mau cari obat untuk kasih minum. [laugh] I: dan marah bilang apa itu? R: yah, nanti dong marah kenapa itu waktu kader2 dong bagi obat filaria, tidak mau ambil minum sekarang sudah kena penyakit dulu baru keluarga atau tetangga datang mau pergi dan cari dokter untuk melayani dia begitu."

medication are foolish and will be perceived as such by their neighbours. One man, a farmer from Maritaing (C40) claimed the woman in the drawing who did not comply would suffer ridicule because of her refusal of the government programme:

*...the one who did not comply, in my opinion, at the most, she gets [LF] we all will ridicule her at the time... because she was not happy to accept the programme from the government because this government programme is good. That is my opinion.<sup>72</sup>*

In all these instances, moral judgement is a public punishment, which will cause individuals to feel shame in the face of their peers or family members. (See section 5.8.2.)

### **Interpersonal pressure**

During discussion of the two drawings, I asked respondents who they would prefer as their neighbour – the woman who complied or the one who did not. As we saw (table 10), many people chose the person who was similar to themselves in terms of their own compliance. In addition, there were some respondents who claimed they would influence their non-complying neighbours by putting pressure on them:

- Man, 48 years, civil servant (C5): *“I would choose to live next to the woman who did not comply so that I could go over to her house and explain to her that she should take the LF meds. My spirit would not be comfortable and I would be disappointed if she then got the disease. If she dies, then we, as neighbours, are responsible for her death.”*
- Man, retired civil servant (previous head of the LF programme) (C6): *“If the lady who did not take the drugs lives next door, I don’t know what her future might be. If she gets it, then it could transmit to us. So we have to give her awareness because she is our neighbour.”*

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<sup>72</sup> Sedangkan yang tidak itu menurut saya ya, paling dia sudah kena kita semua olok-olok dia begitu. ...karena dia tidak senang menerima program daripada pemerintah itu karena program pemerintah adalah baik, itu kalau menurut saya.



- Woman, breastfeeding (NC9): *“With the non-compliers, we can show her the right direction and she may want to follow. We won’t force her, but if we show her the right way again and again, for sure she will think, ‘ya, I want to follow too.’”*
- Man, farmer, elementary education (C40): *“After the complier takes the drug, she can tell her neighbours how different she feels now and how much better. She can say how it would be better if we all went together [to take the drugs]. So she can influence her environment, her neighbours that way. Those who haven’t complied yet will be influenced and follow her because she already has experience.”*
- Man, 57 years, teacher (NC51): *“If the non-complier lives next door, then we need to help them and explain to them that they need to take the medication. That is what we can do to help. If you don’t take it, this is what will happen to you... your future.”*

These individuals all speak about exerting pressure on a neighbour to comply. The use of such pressure is subtle in most cases. One man (C5) goes so far as to say that his non-compliant neighbour’s death would be their responsibility if they did not influence her. One woman (NC9) believes people will be convinced after hearing about the treatment repeatedly over time. She gives the impression of someone who will not give up in her attempts to get her neighbours to comply with treatment!

### **5.7.5. ALTERNATIVES TO COERCION**

The Indonesian government is familiar with the practice of influencing compliance by providing rewards for behaviour. In my own research, I was required by the National Institute for Health Research and Development in Jakarta to give each interview participant a token of appreciation for their time. It was suggested that I give them something health-related and so I gave to each participant a towel and a bar of soap. I offered this gift at the end, rather than the beginning, of the interview, so as not to influence respondents’ decisions to take part. It is possible, however, that in some villages other people may have heard

about my gift and this may have been an incentive for them to participate in the interview.

One incentive mentioned frequently was the fact that provision of the LF drugs was free of charge. One business man from Mebung (C14) said that this increased acceptance of the programme. A fisherman from Ampera (C10) claimed that if he had to buy the drugs, there was only a 50-50 chance that he would take them. A farmer in Tominuku (C20) told me that one of the reasons he walked 5 kilometres for the treatment was because it was free. A man in Maritaing (C40) said that if the government offers the drugs for free – then they will accept with a happy heart. Not everyone, however, felt that free provision was always a good thing. One man, a community leader (C30) spoke of people's scepticism and distrust of free gifts from the government, because of the history surrounding the Community Party (PKI) in Indonesia in 1965. However, he added that it was better that the LF drugs were offered free of charge because not everyone could afford them.

Of course the most positive and perhaps obvious reward offered by the MDA is the prevention of disease. As one man in rural Mausemong (C38), expressed it:

*"...but I feel that in neighbourhood X here, because they have thinking that comes from a pure and good heart, that they will heal quickly from the disease, so that they take this treatment, not because there is force, but they take it with happiness, so that they drink and can get rid of the disease which is here."*<sup>73</sup>

Many respondents spoke about how the LF drugs would prevent disease (C4; C5; NC9; C10; C14; C20; C21; NC23; C30; C36; NC/C37; C40; C41; NC43; NC50; NC52; C53). Many of them recognised the insurance compliance brought – by preventing the illness now with free drugs, one avoided the possible costs of illness in the future (which included loss of work time as well as treatment costs).

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<sup>73</sup> "tapi saya rasa dusun X ini karena mereka punya pikiran yang timbul dari hati nurani yang baik itu cepat sembuh dari penyakit, sehingga mereka terima obat itu bukan dengan paksa tetapi mereka terima dengan secara sukacita, supaya minum dan bisa menghilangkan penyakit yang ada."

## **5.8. THE ROLE OF EMOTIONS IN MOTIVATING COMPLIANCE WITH LF TREATMENT**

*“The emotions or patterns of emotions that a person experiences at a given time influence virtually everything the person does – work, study, play.”*  
- Carroll E. Izard (page 10)(Izard 1977)

The idea that emotions influence or drive our behaviour is not a new one. James Russell (1991) writes about the seven emotions (joy, anger, sadness, fear, love, disliking and liking) which “belong to men without their learning them” described in a Chinese encyclopaedia from the first century B.C. (page 426) (Russell 1991). Here I treat emotions, (or affects as they are also known), as belonging to the realms of feeling and sentiment, in contrast with rational or instrumental thought processes. Emotions are an integral part of being human and can influence behaviour both consciously and unconsciously.

I begin by briefly describing how emotions are experienced in Indonesian and Alorese culture in order to contextualise this theme. I then examine the emotions described in relation to filariasis and people with the disease, and in relation to treatment and compliance with it. I focus primarily on the emotions of fear, anger, shame, disgust as well as joy and pride, exploring their implications for compliance.

### **5.8.1. SCENE SETTING: THE EXPRESSION OF EMOTIONS IN INDONESIA**

Before describing how emotions are expressed within Indonesian and Alorese culture, two caveats should be stated: 1) despite my intense and prolonged exposure to the Alorese culture and people (the result of living for four years in Indonesia and working there over a period of seven years), there are many aspects of emotion within Indonesian culture that I fail to understand; 2) Indonesia is a country of over 200 million people, with thousands of islands, hundreds of languages and a myriad of ethnic groups and so there is an ever present risk of over generalising what is in fact a highly complex picture. Within these limitations, I attempt to shed light on the subject of emotions, using both my own

and published material. A detailed exposition is not within the scope of this research, but the thesis would be lacking if I did not explore emotions to some degree.

Given their complexity, it is no surprise that emotions can be interpreted differently across different parts of the world. James Russell's (1991) attempt to categorise emotions illustrates this diversity. It appears that there are fewer expressions with which to describe emotions in Indonesia compared with the west. Wallace and Carson found over 2,000 words for emotions within the English language (Wallace and Carson 1973). In contrast, Boucher found only 230 words for emotion in the Malay language (Boucher 1979); the language from which Bahasa Indonesia was derived. Some categories used in English are not found in Indonesian language. For example, the line between what we term shame and embarrassment is blurred in the Indonesian language (Keeler 1983).

The common Bahasa Indonesia word for shame is "*malu*", and covers humility, shame and embarrassment. *Malu* is a highly prevalent emotion in Indonesia and one which may express respect towards another on the one hand, or shame in relation to self, for example, at violating a social norm. The concept is in widespread use to describe, for example, a small child's embarrassment or shyness in front of an unknown adult; a person's reaction to being faced with someone of higher; and a person's emotional state on being discovered to have done something wrong. DuBois described *malu* or shame, "as the chief social sanction" (page 118) in a society where what is most important is what other people say about you. She also described a link between shame and anger in this regard; as reactions to derogatory comments must be met with anger in order to protect reputation (DuBois 1944). Fessler, in his research on emotions in the southwest of Sumatra, found that residents engaged in an assortment of behaviours in order to avoid experiencing *malu* or shame (Fessler 1999). He gave examples such as attending religious services, visiting sick neighbours, participating in feasts as well as sending their children to school. Fessler's and DuBois' findings confirm the power of shame in Indonesian culture to maintain compliance with social norms and to retain membership as part of the group. This

is consistent with my own observations; in modern Alorese society, and in Indonesian society, public shame remains an important social sanction, and so an important motivator for action.

Fear is also a common emotion, and in Alor, is ever present in everyday life: the remote location and the difficult transportation, weather and sea conditions in certain seasons; the unavailability of health care in remote locations; the presence of dangerous infectious diseases. Moreover people live in a world where black and white magic co-exist and where stories of curses permeate the village and urban culture. The Alorese are exposed to fear from their youth, and children face fear frequently – in the context of amusement as well as discipline. I experienced fear-provoking amusement with friends who, in front of their small child, would tell him that I was going to take him away and adopt him. Of course, the parents thought this was amusing as they continued to embellish the story; meanwhile, the child's fear increased with the thought of being separated forever from his parents. I usually stopped the game, telling the child it was okay, I would not be taking them away on a big airplane to some faraway cold country.

Parents and community members use fear as a way to raise the child correctly in his social environment. In neighbouring East Sumba, whenever small children saw me coming in a remote village, they scattered like little chickens – running as fast as they could to get out of my way, sometimes falling into the deep ravines on either side of the road. I was obviously disheartened by this fear and asked a colleague why the children were so afraid of me. I was told that the parents, in order to keep their children from wandering after school, told them that white people were out there who would cut off their heads and eat them. This “warning” came from the Sumbanese traditions of planting the heads of their enemies under the main poles of their houses and rumours of the Dutch having similar practices when building bridges. In Alor, DuBois writes of a similar story where naughty children were threatened with being sold into slavery (DuBois 1944). Such stories are still told today to children to discipline them (personal communication with Dr. František Kratochvíl) and to keep them in line with the social norms of their communities.

The regime of fear introduced in childhood continues into adult life. Fear in Alor and in Indonesia is marked by strong traditional beliefs in the supernatural, which have morphed over time with the arrival of Christianity and Islam, but have not entirely disappeared. In Alor, with the introduction of Christianity into the culture, a *mélange* of animistic and Christian beliefs exist. An Alorese friend of mine living in Kalabahi told me she was forbidden to go out at night while she was pregnant, for fear that Satan would harm her or her unborn child. The night before I left Alor, she came anyway to my party in the evening. When I saw her, I asked how she was able to come out in the evening, so late in her pregnancy. She smiled and pulled from her thick black hair, a large 6 inch nail stuck into her pony tail. This nail offered her protection and enabled her to travel at night. I heard many more stories during my time on Alor – of people flying, of curses on households, of the effect of the supernatural on all electronic equipment, of village leaders who had supernatural powers, of people nearly dying as they fought the evil spirits. Alor is, amongst the people living in Nusa Tenggara Timur province, known as one of the major sources for black magic. It is so renowned that my research assistant, from Kupang, did not want to travel into the interior of the island for fear that he would be poisoned. During his time on Alor, he carried with him his Rosary at all times, for extra protection against the black magic of Alor.

There are also differences between different parts of Indonesia in the expression of emotions. Browne describes “*ngamuk*” (as in “running amuk”) as mental or social suffering due to the political context in Java where significant repression of emotion and dissent exists (Browne 2001). He writes (1999) that this repression is caused by a “convergence of public culture, and social and political forces that seek to suppress dissent” (Browne 1999), page 210). In a similar manner, Warwick writes of Indonesian government officials having been forced to silence any criticisms of the family planning programme during the New Order regime (Warwick 1986). During this time of military rule under President Suharto, no protest was permitted and voicing opposition risked “disappearing” or ending up in jail. This extreme suppression of emotion became ingrained during the New

Order (1965 – 1998); it is not a part of Indonesian culture *per se*, but arose as a means of survival during this period and continues today.

Within institutional life, a form of emotional suppression can be found in what has become known as “*asal bapak senang*” which translates into “to make the boss happy” (personal communication with Mrs. Heny Nggadas) meaning to keep the boss from negative information, including problems, criticism or dissent. I experienced the effects of this cultural adage in my work with Indonesian government officials. I was sometimes asked to voice criticism or dissent by the district health staff to the head of the health authority. My role as an international consultant allowed me more freedom while they remained bound by an obligation to keep their boss happy.

The people of Alor are culturally different from those of Java or Bali. Those living in some northern and eastern parts of Indonesia<sup>74</sup> are generally more aggressive than the Javanese, for example, in terms of expressing their anger. In contrast, in NTT, people are less expressive than the Javanese in terms of stating their dislike of or disagreement with someone, preferring to remain silent (Personal communication with Mrs. Heny Nggadas). The tendency to contradict what you feel in order to be polite, is termed “*basa basi*” in Bahasa Indonesia<sup>75</sup>. A European Catholic nun, working as a nurse for the last 35 years in the NTT province, told me about the clinical manifestations of such emotional repression, citing the cases of stomach ulcers and gastrointestinal problems she encountered in her clinics over the years. Family pressures and obligations were also important factors in creating this stress.

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<sup>74</sup> Nusa Tenggara Timur (NTT province includes Alor), Maluku (the Spice Islands), Papua (formerly Irian Jaya) and the Batak people of northern Sumatra

<sup>75</sup> This might apply in a situation where you want to go to bed because you are exhausted, but you are polite and stay awake for more discussion or you accept a dinner invitation from a boss when you have other plans. (Personal communication with Sebastian Fernandez)

## 5.8.2. EMOTIONS AND LF

### Fear

Fear was the emotional state most commonly referred to in the context of LF and its treatment. The symptoms of LF instilled a good deal of fear in people. In discussion with a 28 year old mother of two children living in an endemic area (C35), she told me: *"I'm afraid because we women here get filaria, what will happen; if for men, we know. We women, what would happen if we women got filaria, what kind of symptoms would it have? I am afraid."*<sup>76</sup> This woman lived in an area with bancroftian filariasis where the known manifestation was hydrocele in men. She struggled to understand what symptoms would be apparent in women and the uncertainty frightened her.

People also told me of their fear of LF in terms of their own personal risk of infection. They may or may not have understood correctly how they could contract the disease but they nevertheless saw transmission as a possibility and that frightened them:

- A 35 year old man living in a suburb of Kalabahi, Mebung, who works in private business (C14), *"Yes, that is we want to be afraid, meaning that there is a feeling like fear that it [LF] will transmit or whatever, but there are no other feelings, only the feeling of fear is there."*<sup>77</sup>
- A 53 year old Timorese woman living in Kalabahi (C55), *"Afraid, yes... I see someone with a leg that is elephant-like, we want to be close, we are afraid though, afraid it will transmit..."*<sup>78</sup>
- A 25 year old man from Fanating (NC26) who works as a labourer for the government; asked if he was afraid working in the fields with his neighbours who both had *kaki gajah*, *"Yes, even I am afraid because what if it transmitted."*<sup>79</sup>

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<sup>76</sup> Takut karena kita perempuan ini dapat filaria, bagaimana kalau laki-laki itu dikasih tahu. Kita perempuan ini gimana kalau kita perempuan dapat filaria, ini bagaimana dia punya ini gejala2 bagaimana. Takut.

<sup>77</sup> "Ya artinya kita mau takut artinya rasa seperti takut dia berjangkit atau apa tapi perasaan lain tidak ada hanya perasaan takut itu yang ada."

<sup>78</sup> "Takut, ya... saya lihat kaki terlalu gajah itu, kita mau dekat, kita rasa takut begitu, takut jangkit..."

<sup>79</sup> "Ya, memang rasa takut karena jangan sampai terjangkit gitu"



Whilst the two people from Kalabahi and its suburbs were more removed from people living with LF on a day to day basis, the 25 year old man from Fanating had direct contact in his daily working life with two neighbours who had elephantiasis of the leg.

It also emerged that fear might be generated not only by the disease itself but by its symbolic significance. A 41 year old university educated man living in Kalabahi (C49) related his fear when he saw people with LF to stories from his elders as a child that the disease was caused by a curse. Now, he said, he thinks the old people told this story to their children to keep them out of the mud. In similar vein, a 25 year old man from Fanating (NC26), a village where LF is highly endemic told me people were afraid of the curse of LF, sometimes related to jealousy of someone else's attainment in life. He talked about other people's fear, rather than his own. He described two kinds of lymphoedema of the leg or *kaki gajah*: the swollen leg caused by a curse which does not have any sores, and the swollen leg caused by contact with the mud which does. People are able to know the cause of their disease on the basis of both the presence of sores and the pace of its arrival.

Fear of the disease was clearly a key factor motivating compliance. When asked how afraid he was of LF, a man from Mausemong (NC/C37) answered "*little, big, medium, small and everything, so personally I don't want it, so it is better if I prevent ahead of time.*"<sup>80</sup> A woman from Fanating (C54) told me that she was afraid of the disease and so must take the pills. She added that those in her family who did not go to get the treatment were now afraid. These two accounts were from people living in LF endemic areas, where they would have come into even daily contact with people with signs of the disease.

In high prevalence areas, regular exposure to LF would instil fear into some residents and prompt them to protect themselves; while in non-endemic regions,

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<sup>80</sup> "*Sedikit, besar, sedang, kecil dan seterusnya segala itu tentu secara pribadi saya tidak mau. jadi sebaiknya saya cegah lebih dahulu.*"

some people would need to learn about the disease before recognizing its importance. A 38 year old fisherman from Ampera (C10), a suburb of Kalabahi, told me that they had not understood what *kaki gajah* or *boa besar* was before, but once they did, they felt fear and felt it was better to take the treatment rather than get the disease soon.

Fear was a potent motivator for protection, but respondents often also expressed fears about the treatment itself – of the way in which it was administered, its side effects, and the unknown. One source of fear, paradoxically, was the free provision of the drugs. People drew on past experience of free drug administration, based on eye witness or hearsay. A community leader from Fanating (C30) related the trauma people experienced in 1965 to current fears about the free provision of LF treatment:

*Yes, these are a lay or non-expert community, a community who does not understand, who are rooted in their existing traditions, and who have people they trust more than others, because there has been a lot of trauma for them, lots of trauma. If there is free distribution, often they come to me and say, this better not be like G30S/PKI. PKI people gave away free things, at the end we had family who were all killed, murdered. The free rice which is brought by the 300 and distributed now, many come and ask me [about it], I say that it is not [associated with PKI], and that it is even from the president. If the president dies, we die; if he is still alive, then we live...<sup>81</sup>*

As a result of this fear, this respondent told me that free items were not readily accepted when they were distributed. 1965 was the year in which a coup on President Sukarno was attempted in Jakarta, called the 30<sup>th</sup> September Movement or *Gerakan September Tiga puluh (GS30)*. The PKI (*Partai Komunis di Indonesia* or Indonesian Communist Party) party was eventually blamed by the Indonesian

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<sup>81</sup> “Ya, itu namanya masyarakat awam, masyarakat yang tidak mengerti, dia tetap berdasarkan dengan dia punya tradisi yang ada, dia punya orang lebih dia percaya daripada orang lain, karena banyak yang trauma bagi mereka, banyak yang trauma, kalau bagi cuma-cuma ada yang biasa datang tanya saya bahwa jangan sampai sama dengan G30S/PKI, PKI orang bagi barang cuma-cuma, akhirnya kita punya keluarga mati semua, terbunuh, beras sekarang baru bawa 300 ini yang dibagi ini banyak yang datang tanya saya, saya bilang ini memang tidak, ini memang dari presiden kalau presiden mati, kita mati, kalau presiden masih hidup kita pun masih hidup...”

army for the attempted coup despite their denial of involvement. In October 1965, killings began against people associated with the PKI across the country. Scholars believe at least half a million died and perhaps as many as 100,000 people were imprisoned at the end of the 1960's as a result of retaliation against the PKI. (Ricklefs 2001) Ricklefs writes that "these killings left an indelible mark upon many Indonesians" (page 347). One way association with PKI was determined was by receipt of free goods given by them.<sup>82</sup> Such fears influenced people during the MDA for LF when faced with the free provision of drugs, reminding them of this traumatic history.

In eastern Indonesia, people generally prefer injected medications to taking them orally. The adult dose for LF treatment in Indonesia consists of four DEC tablets and one Albendazole tablet. Taking five tablets caused fear among some. A 28 year old woman (C41) from Maritaing told me she was afraid to comply when she saw the number of pills she had to take, saying "*... the big and small drugs were too many; I want to take it but feel afraid, so I asked my neighbour if people said we had to take them all.*"<sup>83</sup> Another (C35), from Fanating told me there were so many pills she was afraid of what would happen if she took them all. Interestingly, both women from two different endemic areas took the treatment despite their fears.

One man from Tominuku (C19) where the LF research is being conducted by German and Indonesian researchers told me he was afraid of having his blood taken, as he had never had that done before. This fear became one of the major impediments to the research in this area. To counter this, the research teams gave eggs and packages of instant noodles as incentives for allowing blood to be taken. This good intention backfired and resulted in more fear – people believed their

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<sup>82</sup> I also believe that this trauma affected my ability to get people to sign the informed consent at the beginning of the interviews. Apparently in Alor prior to October 1965 people were asked to sign a blank piece of paper when receiving free goods from political parties and then at a later time, the paper would be brought to them with their signature manipulated to show their involvement with the PKI. I was told that people associated with the PKI at this time, still are barred from government appointments (as are their families).

<sup>83</sup> "*saya sempat tanya tetangga saya karena obat besar/kecil terlalu banyak to'o, saya mau minum rasa takut, jadi saya tanya tetangga dong orang bilang dong orang juga dapat minum semua.*"

blood was being bought from them (for the price of eggs and noodles), to be sold outside of Alor.

In relation to possible side effects, people I interviewed talked about their own past experiences, or those of others they had observed or heard about, which made them fearful of the treatment. A civil servant from Kalabahi (NC22), for example, described his children having taken the LF treatment at school and been ill. He told me that if he had understood more about the treatment, he perhaps would not have been so afraid to see his children in such a state. He told me *"I only see my children take it and go directly to bed, while people with filariasis are still walking around."*<sup>84</sup> He felt it best not to take this treatment, he said, lest he suffer the same fate: *"I feel really fine and not taking it is also okay. Rather that, than I take it too and am dizzy, sleeping, like taking ecstasy, it is better not to bother with it."*<sup>85</sup> A man from Mebung (C25), a suburb of Kalabahi was also afraid to take the treatment initially because after the first treatment, he saw people suffer from side effects for 1-2 weeks afterwards, mostly worms being expelled and dizziness. In the subsequent treatments, people had gotten used to it – a possible reason for his final compliance. A mother of three children living in Kalabahi (NC48) also expressed fear because of side effects. She described her husband and children having taken the drugs and gone straight to sleep, just as the community health worker had said it might happen. This woman did not comply. She told me that she was initially afraid of side effects, then of *"angin"* or wind which might be associated with the treatment.<sup>86</sup> Later on though, she simply forgot to take it. Possibly her motivation to remember to comply was weakened after seeing her family's severe reactions.

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<sup>84</sup> *"Saya hanya lihat anak-anak minum langsung tidur, orang yang kena filaria juga masih tetap jalan."*

<sup>85</sup> *"Saya rasa aman-aman saja dan tidak minum juga biasa-biasa saja. Daripada saya minum sama dengan pusing tidur sama seperti minum ekstase lebih baik tidak usah begitu."*

<sup>86</sup> *Angin* or *masuk angin* is a culturally specific illness in Indonesia. It literally means "wind" or "wind enters". The closest comparison I can make is getting a chill. For example, you can get it by sitting on the ground without something underneath you, bathing at night or travelling at night. One way to treat it is to have massages that are able to find the wind in your body and work it out. Another interpretation is that it can also be a bad spell coming into the village or into a house (Personal communication with Sebastianus Fernandes).

A man living in Tominuku (C19), a highly endemic area of Alor, spoke of the fear among some because, after the first treatment, some people experienced swelling in their legs (a potential side effect of the treatment when people are infected with LF; the swelling usually reduces shortly afterwards). In this particular village, the manifestation of chronic infection with timorian filariasis is lymphoedema of the leg from the knee down. Imagine that the health staff comes and tells everyone that this treatment will cure or prevent infection and then you witness a neighbour or a family member suffering from a swollen leg after taking the medication. It would appear that the medication caused the disease.

Other fears stemmed from imagined, as opposed to observed, consequences. A man from Maritaing (NC43) told me he was afraid to take the LF drugs because they were new and he feared they might bring on another disease, like cancer or a tumour. An older man (NC50) from Maukuru also told me that people in his village were afraid of the side effects because the drug was new. Both men expressed fears relating to the unknown nature of something new. In many instances, the fear expressed stemmed from ignorance about the way in which the treatment works. A resident of Kalabahi and mother of six children (NC52), told me that in the beginning of the MDA, the community health worker did not explain well enough about the treatment and as a result, people did not want to take it. A man from Kalabahi (NC22) spoke of his uncertainty over whether the swollen leg came from taking the medication or from the disease itself. This fear caused him to search for more information. Interestingly the two people who mentioned their fear of the unknown and the need for more information were from the district capital. They may perhaps demand more information as urban dwellers and would have become accustomed to a more steady flow of information than people living in the rural areas.

In the absence of reliable information about a medical intervention it seems that myths abound and are perpetuated. A woman living in Mausemong (NC39) told me about a man in her village who had surgery for hydrocele in Kalabahi (the district capital) and died afterwards. I was aware of this story and had heard that the reason the man died was that following his surgery he was not told to avoid

heavy work until his stitches were removed and his scar had healed. It seems that his wound opened while working and he died as a result. Mausemong is one of the most remote villages in Alor and requires a 20 kilometre walk to the nearest health centre (the road is so ruined that a car takes as long as walking). NC39 told me of three more men in her village who suffered from hydrocele who had been offered a chance to reduce the hydrocele through surgery in Kalabahi. They had refused because they were afraid to die<sup>87</sup>. As a result of this man's death and the way that news travels on Alor, few people were willing to go for the hydrocele surgery.

Death being perhaps the ultimate fear among most cultures and peoples, it was perhaps not surprising that it featured in the accounts of those I interviewed. Although intangible because of its uncertainty, the fear of death can be said to be one of the most intense motivations for action, as it responds to most base of human functions – to live.

The influence of fear of death on compliance with treatment was, however, complex since it depended on whether the greater fear was for the perceived effects of the treatment or those of the disease. Within the context of LF medication, the fear of death can be seen as motivation to avoid treatment feared to be life threatening and as motivation to take the treatment when the fear is that LF is associated with death. A woman from Kalabahi (NC52) told me they take the LF treatment *because* they are afraid of dying. A school teacher in Kalabahi (NC51), on the other hand, told me that he was afraid of the disease as it could potentially shorten your life, but he did not comply with LF treatment because his belief in traditional medication, like the use of boiled papaya leaves, was stronger. His regular use of this remedy was, he believed, an equally effective prevention or cure of LF. Both these people live in an area of Alor where there is no LF, so it is probable that they did not know that LF is a disabling rather than a fatal disease.

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<sup>87</sup> NC39's accounts of men's refusals of the free hydrocele surgery reflected operational difficulties at the district level. The German Technical Cooperation and the District Health Authority had invited several surgeons from Jakarta to come to Alor to perform hydrocele surgeries for men on Alor; however there were few willing surgery patients because of rumours related to this man's death.

Some respondents spoke of their lack of fear with regard to LF or its treatment, often justifying this with reference to their faith – in God and in the treatment. A 43 year old farmer (C40) with an elementary education living in Maritaing said “*there was no feeling of fear in fact we felt gratitude to God [for the treatment].*”<sup>88</sup> He used a phrase “*bersyukur*” which can be understood as being grateful to God and being fortunate. A 51 year old woman (C57) living in Kalabahi attributed her lack of fear of the disease God is with everyone. Both of these people qualify their lack of fear or their security by speaking of their gratitude or faith in God. One woman (C4), a minister in training in a mountainous village of Alor told me that she was not afraid [of LF] after taking the treatment because she believed that the disease has medicine to cure and prevent it. (She was new to the area and would not have been exposed to LF from the area she came from). Another woman (C41), living in coastal Maritaing, was not worried about getting LF. Both of these women took the treatment, and so probably felt safe.

### **Shame**

After fear, shame was the emotion most commonly linked with LF. Since the clinical manifestations of the disease are often visible (for example, where there is physical evidence of enlarged legs or scrotum) and because of the disfigurement they cause, it is not surprising that people report having strong reactions to seeing others with the disease. The type of LF present in an area determines what kind of chronic manifestation the disease takes on, but whether a hydrocele or a lymphoedema, both are eventually visible to the public. Although a hydrocele can be hidden underneath a sarong, it will eventually become obvious that the person is suffering from hydrocele, either because he no longer wears trousers or because of village rumours. Respondents’ comments revealed an awareness of the sense of shame that these manifestations of the disease could cause sufferers to feel:

- A 48 year old man from Flores living in Kalabahi (C5): “*If we see a man with a big leg walking to market, he is ashamed in front of others. He feels inferior because people see he has a big leg. Before there was no*

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<sup>88</sup> “...*rasa takut tidak ada malah kita rasa bersyukur...*”

*treatment to prevent the disease, now there are not so many people with big legs anymore, only old people."*

- Farmer from Mausemong (NC/C37): *"If I got LF, I would be ashamed in front of my friends in such a condition - people would talk. I would be ashamed to mingle with friends because my condition would be different from my friends."*
- 28 year old man from Maritaing (NC43): *"Men have hydrocele here. I have had it too twice..... There has been someone here who has a big hydrocele and he is ashamed to be seen. You can see his genitals."*

Respondents also spoke of their own shame should Alor be known as a base for LF. A young farmer from Mebung (NC16) told me of his feelings of "*malu*" at seeing people with hydrocele in the LF film shown in his village. He and his family would feel ashamed and uncomfortable if outsiders saw Alorese people with big legs. He wanted his district to be healthy and so felt they should take the treatment. This man applied the word "*malu*"; first, to his own sense of shame should Alor be perceived as a stricken area and second, at his embarrassment at seeing someone's enlarged genitals on a large film screen in public. It is worth noting that one of the terms for the genital area in Indonesia is "*kemaluan*", incorporating the root word "*malu*".

Despite their awareness of the shame felt by people with LF, and despite their own sense of shame at the idea of their community being one hit by the disease, respondents' accounts also revealed considerable empathy for sufferers. A number of responses to the question "How do you feel when you see someone with LF?" revealed a strong sense of pity and sympathy:

- A 38 year old fisherman from Ampira (C10): *"When I see someone who has it, I am really sad, because they have a hydrocele and when they walk, it is difficult for them. Poor them. People with the disease feel inferior and often they feel ashamed. They don't dare to be in the public eye - they are always behind, because to look at them is not good."*



- A 38 year old woman from Mebung (C15): *"I feel sorry for them because it may be a hereditary disease because there is no swampland here."*
- A 30 year old man from Welai Selatan when talking about his father's own infection with LF (C21): *"I felt badly because we could not get help for my father and that he had tried to get an operation in Kupang but he never managed to."*
- A 55 year old woman from Maritaing (C42): *"I feel fear and horror, but they are human, so what can we do? They are elders (older people) and so must be helped. Everyone treats them the same, mingling and sitting together with them."*
- A 23 year old farmer from Mebung (NC16): *"My feelings when I saw the images on film are funny and also I have pity on them."*
- A 38 year old man in Kalabahi (NC22): *"I have no real feelings when I saw a man from Tominuku with lymphoedema."*

How LF sufferers are viewed is no doubt influenced by one's familiarity and frequency of contact with them. Some people lived in areas where they would come into daily contact with people with elephantiasis in the market, for example, while others saw images of hydrocele and lymphoedema on the DHA/GTZ film brought to their villages as part of the socialisation campaign. Those who lived in the endemic areas (Welai Selatan and Maritaing) spoke of helping sufferers and of helplessness in finding a cure. They could understand first hand how important it would be to assist these people and to minimise any stigmatisation they may feel. A 51 year old woman from Kalabahi (C57) suggested the notion of retribution might also inspire sympathy with sufferers; since feelings of nausea towards them may result in the disease being visited on oneself.

As noted above, shame has a strong connection with social norms. A 28 year old woman in Maritaing (C41) described the shame associated with getting sick because of non-compliance with treatment. Shown the drawing, she recounted that the woman who did not comply will be yelled at by her neighbours and her family when she got sick with the disease. She added that this woman would be ashamed

and also would be angry with them<sup>89</sup>. In her description of the non-complier, C41 explained how she would react to the fact that her non-compliance and subsequent illness had been discovered. Her emotional reactions were deeply rooted in a system where social norms were instilled.

## **Anger**

Anger was also frequently referred to in the context of treatment-taking and health workers, non-compliers, spouses and LF infected people. References to anger have already been mentioned in the context of coercion, for example, where health staff was described as being angry with non-compliers. People themselves noted that the doctor would be angry with them if they did not take the treatment. A community health worker (NC12) herself described following non-compliers to their houses and being angry with them so that they complied. Another woman (C57) talked about the local community leaders being angry with non-compliers if they became ill later on.

Respondents talked about their anger towards those who did not take the treatment. A woman from Mausemong (NC39) spoke of being disappointed and angry with those who did not take the drug and that they will now be afraid to die. Anger contributes to the maintenance of the norm of compliance. A man from Tominuku (C19), where *B. timori* was highly prevalent, spoke of their collective anger towards non-compliers:

*“Indeed at the very beginning we were also angry, everyone was really angry from the distribution towards those who did not drink [the medication], soon we here will also get the disease itself, but after awhile we mingled again as usual.”*<sup>90</sup>

C19 talks about the initial anger of those in his community with non-compliers, and then after some time, they seem to go back to normal socialising<sup>91</sup>. In rural

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<sup>89</sup> This reflects DuBois’ earlier statement (section 5.8.1.) describing a link between shame and anger whereas derogatory comments must be met with anger in order to protect social reputation.

<sup>90</sup> “Memang yang paling pertama kami ju marah semuanya marah habis dari perbuatan si itu tidak mau minum nanti kami ini ju bisa kena lagi tapi awalnya setelah itu kami bergabung secara biasa”

<sup>91</sup> This has resonance with the description of DuBois (1944) of quarrels she observed in Atimelang, where, as an informant told her “[Quarrels] don’t last long. They must forget and eat together” (page 119).

areas like Tominuku, which is a relatively small village, quarrels may be public affairs and a sustained conflict would be difficult to maintain in such a closed society. In his description of the drawings, a 43 year old man from Maritaing (C40) talked about the ridicule and anger a non-complier would receive from people living around him:

*R: In my opinion, if she – the non-complier - at the most is like us in one neighbourhood, [except] we the others have already drank the medication. Then the one who didn't take it, at the most, she is alone, which it might happen that she will be attacked by this disease. Alone, because she will not have energy to hold out; only because she doesn't have prevention. So it will be easy to be attacked by the disease. That is my opinion.*

*I: So if that's so, what will the other people do to help her? Will they say, "oh dear, this person didn't comply"... or "they don't want to prevent themselves" or...*

*R: In my opinion, next they will ridicule her, then they will be angry with her. Then the neighbours will say "you take the risk already because you didn't want [to comply], we all were different, we drank [the medication]. Then you don't want to drink, you alone get this disease. At the least, we, as humans [laughing] think that we must speak like this."<sup>92</sup>*

He is describing publicly shaming of the non-complier through the use of anger and ridicule. This behaviour is also described by DuBois (1944):

"Furthermore, it expresses the conscious linkage in Atimelang between shame and anger. This is a perfectly accurate observation of the Atimelangers on their own psychology. What matters is what people say about you, and you protect yourself from derogation by a vigorous emotional discharge of anger. In this society, which has no organized police force and has only a recently introduced system of litigation, shame acts as a chief

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<sup>92</sup> R: menurut saya kalau dia yang tidak minum ini, paling nanti seperti kita di dalam satu kampung, kita yang lain sudah minum. Terus satu yang tidak minum itu, paling dia sendiri yang nanti akan diserang penyakit itu. Sendiri, karena dia kan dia punya daya tahan tidak ada, hanya dia tidak ada pencegahan... Jadi muda diserang penyakit. Itu menurut saya.; I<sub>1</sub>: kalau begitu, apakah ada orang yang lain akan datang bantu dia? ....akan bilang aduh ini orang tidak minum.....mereka tidak mau mencegah sendiri atau...; R: ini kalau menurut saya nanti ada olokan<sup>2</sup> terhadap dia, nanti orang marah dia, [ ] jadi di tetangga bilang ya itu lu punya tanggung resiko sudah karena lu tidak mau, kita yang lain kita minum. Terus lu tidak mau minum, lu sendiri yang kena penyakit ini. Paling tidak kita, namanya kita manusia [laugh] berpikiran harus ngomong begitu

social sanction. Ridicule or derogation is simply the external expression of what a person feels as shame. It is a pattern, as we have seen, established early in childhood.” (page 118)

Of course modern day Alor has a police force and there is now a system of litigation, so her observations are slightly dated in that regard; however, her observation of ridicule, shame and anger are still a part of social interactions in the village and serve as a way of maintaining the social order and adherence to social norms.

Some respondents described feeling no anger towards those who did not take the treatment. A male complier from Mebung (C14) told me that if his neighbours did not take it, he would not be angry; in fact he would have no feeling at all, no feeling of disappointment, no problem. He added that it is each person’s opinion. He comes from an area in which the disease was not present and was married to the community health worker who distributed the drugs from his household. It is possible that his comments stem from his understanding that his village was not under great risk for LF. Describing the drawings, a woman from the nearby village of Fanating (C53) predicted that the non-compliant woman would get the disease. If that happened, people would not be angry with her, because it was her choice alone. Both of these comments complement the subsection in social norms (5.4.4.) where some people reported that any decision to take or not to take the treatment was autonomous and was not threatening to the group in anyway. These two individuals discussed here described without emotion (not anger, disappointment, shame) how people may refuse taking the treatment. They are essentially not supporting enforcement of the social norm to comply with treatment.

### **Other emotions expressed in the context of LF**

References were made in respondents’ accounts to other emotions associated with the LF treatment. Although mentioned less frequently, these emotions were also important in influencing decisions to comply.

#### ***Disgust***

Two people described feeling disgust when seeing people with LF. As distinct from the sympathy and pity seen earlier, they spoke of their disgust at seeing people with chronic manifestations of the disease. A farmer from Mebung (NC16) said he felt *nauseated* when seeing someone with the disease, adding he also felt dreadful and afraid. Another woman (C36) said that she *felt sick* when she saw someone with the disease, and that it even caused a physical reaction in her – she started to itch. These emotional reactions – feeling sick and nauseous – were described by Curtis and Biran as part of the disgust humans feel when in the presence of someone who is sick (Cave and Curtis 1999). A further study has shown that disgust may offer an inherent protection against disease (Cave and Curtis 1999).

Further anecdotal evidence of disgust towards people with clinical manifestations of LF was seen during my field work in 2005. In a rural health centre, my supervisor and I observed training activities for people with LF on the promotion of good hygiene for affected limbs. Health staff demonstrated how to wash the swollen legs for the 15 attenders. One woman sat with tears streaming down her face as her leg was washed by a district official. Asked why she was crying, she explained that it was the first time someone had ever touched her leg. Other people's disgust caused her great suffering as an infected person.

### ***Joy/Pride/Happiness***

Several people reported being happy about the treatment for LF, and the way in which it was administered. One 48 year old man living in Kalabahi (C5) was happy that there was no force used in the MDA. A 35 man from Mebung (C14) spoke about his happiness after taking the medication.

*I: Sir, how did you feel after taking the medication?*

*R: At that time, we were weak, and only wanted to sleep, we couldn't work at anything. The strength of the dose was already gone by the afternoon and our bodies had already come back to normal.*

*I: After that, how did you feel?*

*R: A good fresh feeling.*

*I: Did you feel anything else?*

*R: We felt happy.*

*I: Why did you feel happy?*

*R: Ya, because before we took this medication we were like wanting to be sick but at a certain moment, the feeling went away and we felt that our bodies were really good.<sup>93</sup>*

Another woman (NC9) who did not comply because she was breastfeeding described her pride and happiness about her village and their compliance with the treatment. She had helped the community health worker with the distribution.

*R: With a big heart and a feeling of pride I am thankful for primarily the issue that this medication can also prevent, therefore they are very thankful for this, for when the disease comes or there is a disaster that arrives, before they have already drank the medication which will prevent. Therefore we are proud and thankful.*

*I: Why are you proud?*

*R: Proud for this reason, because we here are in a poor village, we don't have the news, we don't have much of anything. With this disease coming out of nowhere, from where do we have money to buy medication which is expensive....?<sup>94</sup>*

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<sup>93</sup> I: Bapak rasa bagaimana waktu minum obat?; R : Itu kita waktu lemah kita hanya mau tidur saja itu kita tidak bisa kerja apa-apa nanti dia punya dosis kekuatan itu sudah hilang sore-sore begitu kita bisa kita pu badan su normal kembali; I2 : Setelah itu bapak rasa bagaimana?;R : Rasanya bagus segar; I2 : Rasa apa lagi?;R : Kita rasa senang; I2 : Kenapa senang? R : Ya.. karena kan awalnya kita minum itu obat kita seperti ada mau sakit begitu tapi terus tiba-tiba kan dia hilang terus kita rasa badannya bagus baik.

<sup>94</sup> R: Dengan besar hati dengan rasa bangga terima kasih yang lebih diutamakan soalnya dari obat bisa mencegah juga, makanya mereka itu banyak sekali berterima kasih itu soalnya waktu kedatangan penyakit atau musibah itu tiba-tiba tapi sebelumnya mereka sudah minum obat pencegahan makanya rasa bangga terima kasih...; I1 : Kenapa bangga? R : Bangga soalnya gini ya.. bu,pak, karena kami disini desa miskin

This woman was proud and happy that her village received the medication for LF and so would be prepared in the event of an outbreak of the disease. Two people spoke of their happiness that the drug was offered free of charge. A 43 year old farmer (C40) from Maritaing said that because the government offered the drugs for free, they accepted them with a happy heart, while a fisherman from Ampera (C10) said that they did not know the price of the medication but they had heard from the doctor that the drugs were expensive, so they were happy because the drugs were given for free. For both of these men, the cost of medication may have been prohibitive and (C10) said that if he had had to pay, he probably would not have taken it.

## **5.9. HOW DO DIFFERENT INFLUENCES WORK WITHIN THE INDIVIDUAL – CAUSAL CHAIN MAPS FOR COMPLIANCE**

In the previous sections of this chapter, I have explored themes arising from the dataset which relate to compliance with LF treatment. In any one individual, these themes may interact differently, based on personal experiences, beliefs, values and attitudes as well as external forces such as environment and other individuals. In order to understand better how these variables interact within the individual, I have used a novel technique developed especially for this purpose: ‘causal chain maps for compliance’ (CCMCs), to investigate how these interactions influence compliance. This mapping allows an individual’s decision-making process (as evidenced in interviews) to be visually mapped so that the individual variables, their interactions with one another and their influence on compliance can be seen. CCMCs are based on semantic network analysis (D’Andrade 1995), modified so as to be able to represent complete causal chains leading from external factors through psychological concerns to reported behaviour. This general flow of causation (from environmental factors to psychological constructs to behaviour) is

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*kami nggak punya berita kami nggak punya apa-apa tentang penyakit tiba-tiba mendatang dari mana kami punya uang untuk membeli seandainya obat itu mahal...*

common in many current models of behaviour determination, particularly in Bandura's social cognitive theory (Bandura 1986).

### **5.9.1. CASE STUDIES OF INDIVIDUAL MAPS**

I will explore the individual maps of 5 respondents to demonstrate how the causal chain maps show the interaction of different factors and how they influence an individual's decision on compliance.

The following vignettes result from the diagramming analysis itself. After finding the complete causal chain (illustrated by a red line), the underlying reasons for an individual's compliance or non-compliance became clear. These narratives are descriptions of the diagrammes themselves, based on going back to the interview material itself for the crucial statements which support the complete causal chains revealed in the diagrammes.

#### **A non-complying man from Kalabahi (NC51)**

This first map is for a non-complying man who lived in Kalabahi, the district capital. He is 57 years old and is a retired teacher. He is married to a teacher and together they have 6 children. Both he and his wife were taking some extra university courses by correspondence. With this description, it is evident that he is relatively well educated for Alor and still seeks to learn, despite his retirement.

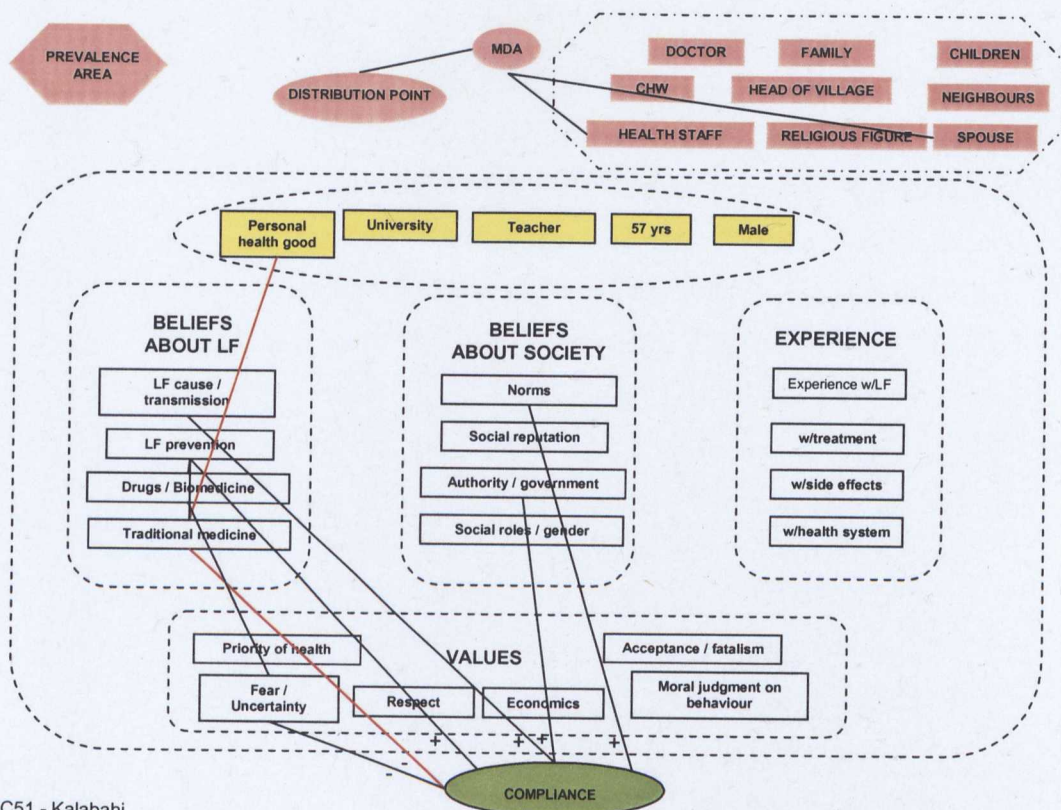
In looking at this man's map, he mentioned four positive influences on compliance (black lines) during the course of our discussion. He demonstrated his understanding of the need for good compliance in the community in order for the drug to work. He told me that in one area, every person had to take the medication and if one person did not want to take it, then the disease could move because it is transmissible; so it was better if everyone took it (illustrated by the black lines from norms – compliance and from LF cause/transmission – compliance). He understood that LF is an infectious disease and that in order for the treatment to work, everyone must comply with taking the tablets.



In another statement (illustrated by the black line from authority – compliance) he stated that if the program was from the government, then he had to accept it; as it was for public health. He also said that it was better to prevent the disease with the medication offered from the health centre, hospital or chemically fabricated medicine. He added that there was traditional medication as well (black line from LF prevention – traditional medicine – compliance). With these four statements he demonstrated his knowledge of the disease and of the mass drug administration, the influence of the social norm to conform by taking the treatment and finally the authority of the government programme to command compliance. By all accounts mentioned here, he should have complied with treatment.

He mentioned one negative comment about the LF drugs, which is that they were chemically manufactured. In his opinion, they contained chemicals inside of them and he was not sure how they might affect his body (illustrated by the black line from drugs – fear/uncertainty – compliance). He then added that it was better to take natural medication and to eat natural foods. He distrusted biomedicine for its chemical properties. He once used biomedicine first for malaria treatment (taking 2 tablets) and then when that did not work, he took papaya leaves (boiled in water and then drinking the water). After a few days he felt better.

With regards to the LF treatment, his wife brought him the treatment the year of the interview (black line from spouse – MDA) and the health staff gave him the medication the first year of the MDA (black line from health staff – MDA). He reported taking the medication the first year; however he said he saw no reason to take it then or to take it now. When his wife brought home the drug the year of the interview, he refused it. For him, traditional medicine and LF medicine had the same use – to prevent disease and keep him healthy. He told me he would continue to use traditional medicine (specifically papaya leaves, a bitter grass (for LF) and massage techniques) and that he would not get sick (illustrated by the red line between personal health – traditional medicine – compliance).



This man may have thought he was complying with the reasons behind the MDA (to eliminate LF), as seen through his statement that he should follow government programmes and his belief that he was preventing his community from LF because of his compliance. The difference is that his compliance was with traditional medications, which, for him, had equal or greater value and purpose to the LF medication.

### A complying man with a history of non-compliance from Mausemong (C38)

A 37 years old farmer who was married and had 4 children lived in a village called Mausemong where he was head of his neighbourhood (*kepala dusun*). Here, the District Health Authority has identified two kinds of LF (*B. timori* and *W. bancrofti*).

This man is a complier with a history of non-compliance; his statements revealed he had complied the year of the interview for the first time, after years of non-

compliance. He began his story by mentioning he had initially tested negative for LF, and so for him, that was a sufficient enough reason for him to refuse treatment (illustrated by the red route from personal health – compliance). He explained to me that if there was no diagnostic test, then people would doubt the medication. People would fear that the medication was not in agreement with the body (*cocok*)<sup>95</sup> thus causing adverse reactions. He had heard that someone had died from side effects after the MDA (illustrated by a black line from side effects – compliance). This represents strong reasoning as to why some people in his community would not want to comply with LF treatment.

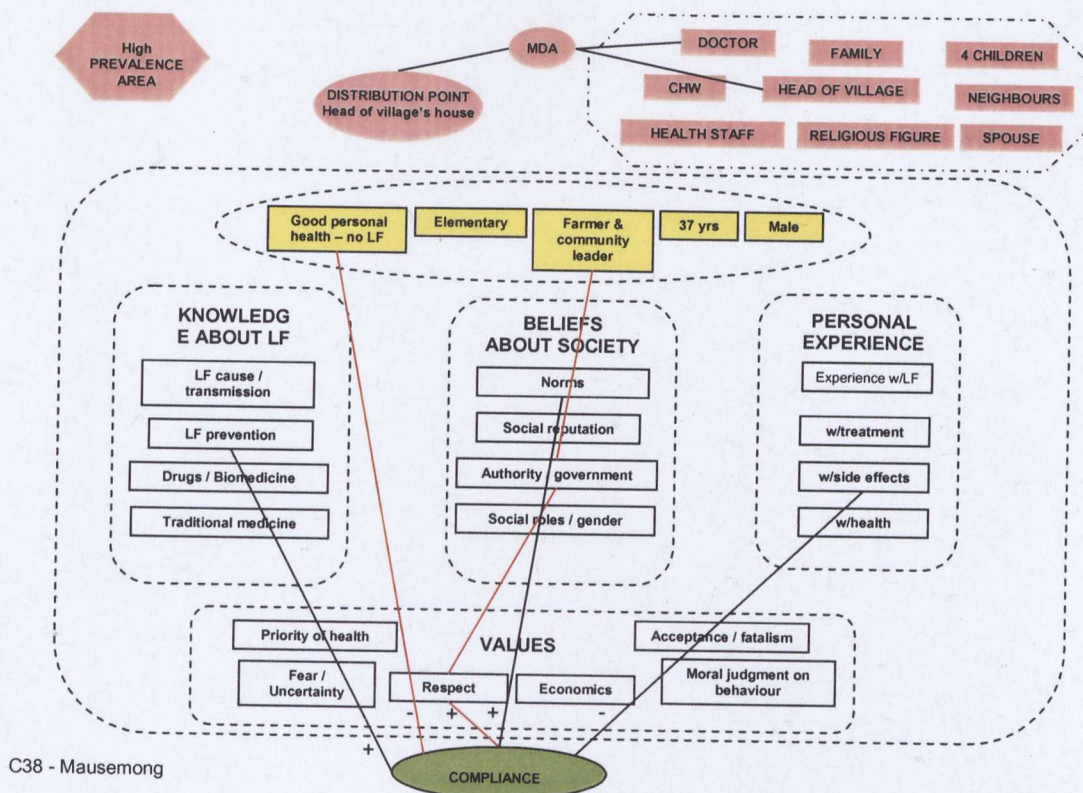
He also mentioned some reasons why he thought people would comply. While talking about the pictures he described the norm to conform by explaining that if the non-complier saw the other woman take the pills and saw that they agreed (*cocok*) with the body then she would take the pills (illustrated by a black line from norms – compliance). He also understood that people would want to take the treatment for prevention and cure of LF (illustrated by a black line from LF prevention – compliance). He believed that those who took it were not forced, but rather complied because of their desire to get rid of LF.

Later in the conversation, he told me that he took the pills this year, because he had become the head of a neighbourhood and it was important for him to comply so that people knew this was a government programme (illustrated by the red route from farmer/community leader – authority – respect – compliance). He understood his own position as a role model and its effect on influencing others in his community to comply with treatment.

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<sup>95</sup> Both this man and NC 51 mentioned drugs being in agreement with the body. They refer to a concept called *cocok* in Bahasa Indonesia which means literally to be suitable or in agreement. Theodore Friend defines *cocok* as fitting, agreeable, conforming. Friend, T. (2003). Indonesian Destinies. Cambridge, Massachusetts, The Belknap Press of Harvard University Press.





Based on the statements in the interview, it seems he changed his mind about complying based on his role as head of neighbourhood rather than any desire to prevent the disease. His map illustrates his two positions (compliance and non-compliance) by giving two complete causal chains – one negative and one positive.

### A non-complying woman from Kalabahi (NC48)

I have referred to this woman in the gender section (5.6.5), where I described how her husband refused her the freedom to mingle with her neighbours on a daily basis, confining her social interaction to larger community meetings. This woman was a 30 year old housewife taking care of her husband of 11 years and her 3 children. She was an outsider to Alor, coming from Rote, an island south of Timor Island. She had been in Alor for 5 years<sup>96</sup>.

<sup>96</sup> In Alor, if not Alorese, then one is forever a non-Alorese. People will be referred to the island or area they came from – *orang Kupang*, *orang Ende*, *orang Rote* (*Kupang people*, *Ende people*, *Rote people*) – rather than being called Alorese; no matter how many years they remain in Alor.

At the time of the MDA, the community health worker explained to this woman about LF at a meeting held at the CHW's house; however my respondent did not attend this meeting. When the health worker brought the drugs at a later time to her house (illustrated by a black line from MDA – CHW), she did not explain anything further about the drugs or the disease, but left them for the woman and her family to take.

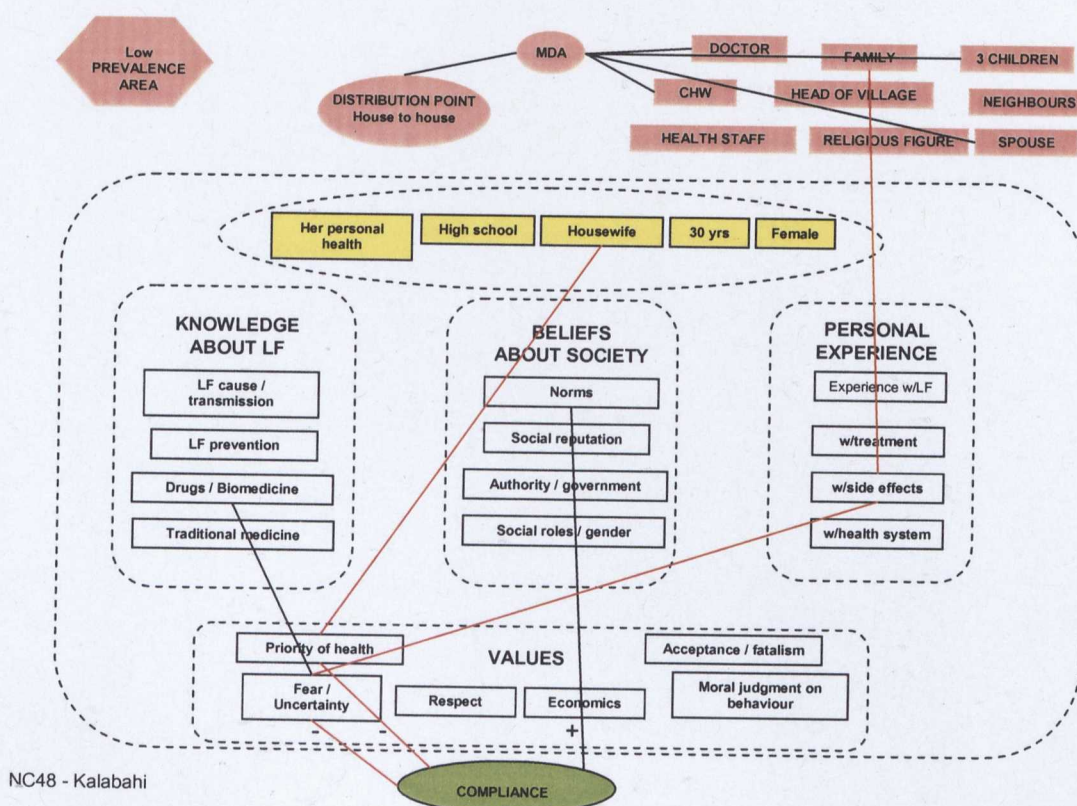
The respondent reported that she forgot to take the pills which were in her house and that they still may be in the medicine cabinet, although she was unsure. She added that she was too busy to take the medication (illustrated by the red lines from housewife – priority of health – compliance). She did give the treatment to her husband and children in the evening after they had dinner and she talked about the negative side effects they suffered from – going to sleep and not waking until the next morning (she said they were unconscious). These side effects frightened her (illustrated by the red lines from family – side effects – fear/uncertainty – compliance).

Initially she had been afraid to take the treatment because of the risk of *angin* or wind (illustrated by red line from side effects – fear/uncertainty – compliance). This is a culturally specific condition in Indonesia which is similar to getting a chill; it can also have a negative effect on the digestive system as well as on general health. She felt that it was better to get sick first and then go to the doctor rather than take drugs for which there are side effects. She acknowledged that prevention was also good, but not at the risk of side effects. She added that maybe the drugs were poison. It is interesting that she gave the drugs to her husband and children first and waited and watched the effect the medication had on them; and then once observing their adverse reactions, she decided not to comply with treatment.

Despite her own non-compliance, this woman was aware of the norm to conform to compliance with treatment. She talked about her fear if everyone else did not take it and that she had heard that everyone had taken the tablets; that it was only her who had forgotten to comply (illustrated by the black line from norms – compliance). These comments suggest that she may have understood the



protection gained from a complying community; making her a free-rider on the MDA campaign in her area. She did know that the medication would prevent lymphoedema of the leg, as was told to her by the CHW, so it is possible that she saw everyone else's compliance (her husband, children and neighbours) as a way of protecting her from LF as well. In fact, she would have the benefit of avoiding side effects and *angin* while at the same time preventing disease.



### A complying man from Fanating (C30)

This man was a community leader in the village of Fanating, an area with a high endemicity of LF, specifically *B. timori*. The village is located within a 30 minute drive from Kalabahi and has a high number of wet rice fields around the village. In the past, achieving a sufficient compliance level for the elimination campaign in Fanating has been challenging.

This man had a fairly good understanding of the cause of LF – knowing that the disease comes from mosquitoes living in the swamps. He recognised that there

were fewer cases today than there were in the past and he credited these changes with the increase of preventive actions as well as the LF treatment itself. He believed that patients with lower amounts of nutrition were more susceptible to the disease than others.

This man's complete causal chain describing his compliant (positive) behaviour revealed that because he was a community leader, he had to comply in order to show those in his community that the drug was acceptable (illustrated by the red line from distribution point – community leader/farmer – authority – compliance). He took an active role in the MDA itself by shouting at everyone telling them they had to comply. In fact, he suggested that for those people who did not attend the MDA, the drugs should be given to their families who would then force that person to take the treatment. The health services rejected this idea.

Apart from his own personal reasons for compliance, he described the positive effect of the norm of conformity to compliance. He said that 100% will not be cured in his village because not everyone came for treatment: all individuals, with or without the disease must come for treatment, and all have to take the treatment; if not, the disease will stay in their village. In his statements, those who did not comply would be responsible for the perpetuation of LF in Fanating. (Illustrated by the black line from norms – moral judgment on behaviour – compliance)

The other influences he mentioned were all negatively associated with compliance. He told me how people were afraid to come for treatment because of adverse reactions. People reported taking the treatment before and having fever immediately afterwards. Because of the presence of these adverse reactions, people cannot work (illustrated by black lines from side effects – economics – compliance and side effects – fear – compliance).<sup>97</sup>

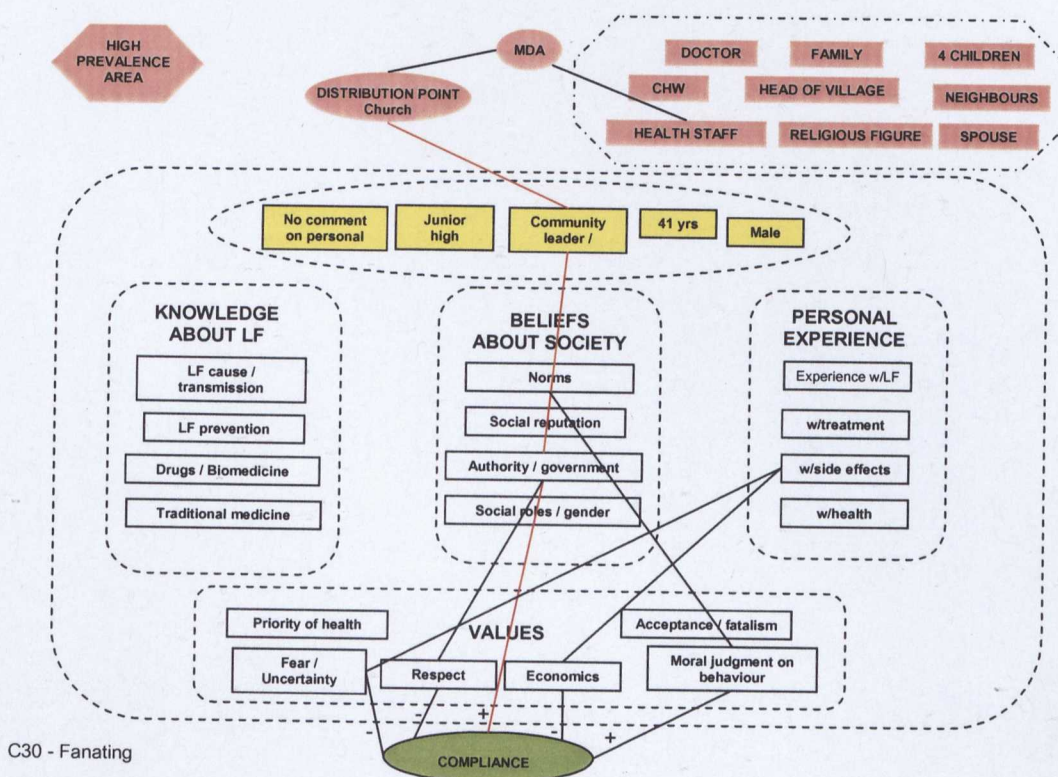
He felt that people in his village were not well educated and as a result, they preferred to use leaves and traditional medicine. They mistook the consequences

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<sup>97</sup> Fanating is highly endemic with *B. timori* and as a result adverse reactions post-treatment would tend to be more severe than in bancroftian filariasis cases.



for disease as relating to “setan” or curses rather than biomedical outcomes. Although he valued the notion that people needed to be aware about LF and that information and education was good, he questioned its effect on an uneducated population. He felt that telling the heads of the households that they must take the LF treatment if they want to ensure their lineage continued and was healthy. He added that government health staff could not motivate the people to comply; rather it had to be someone from within the community. He also mentioned the earlier incidents in 1965 with the PKI (Indonesian Communist Party) when people were traumatised by gifts from the government which later turned into death sentences. These statements are illustrated by a (negative) black line from authority/government – respect – compliance.



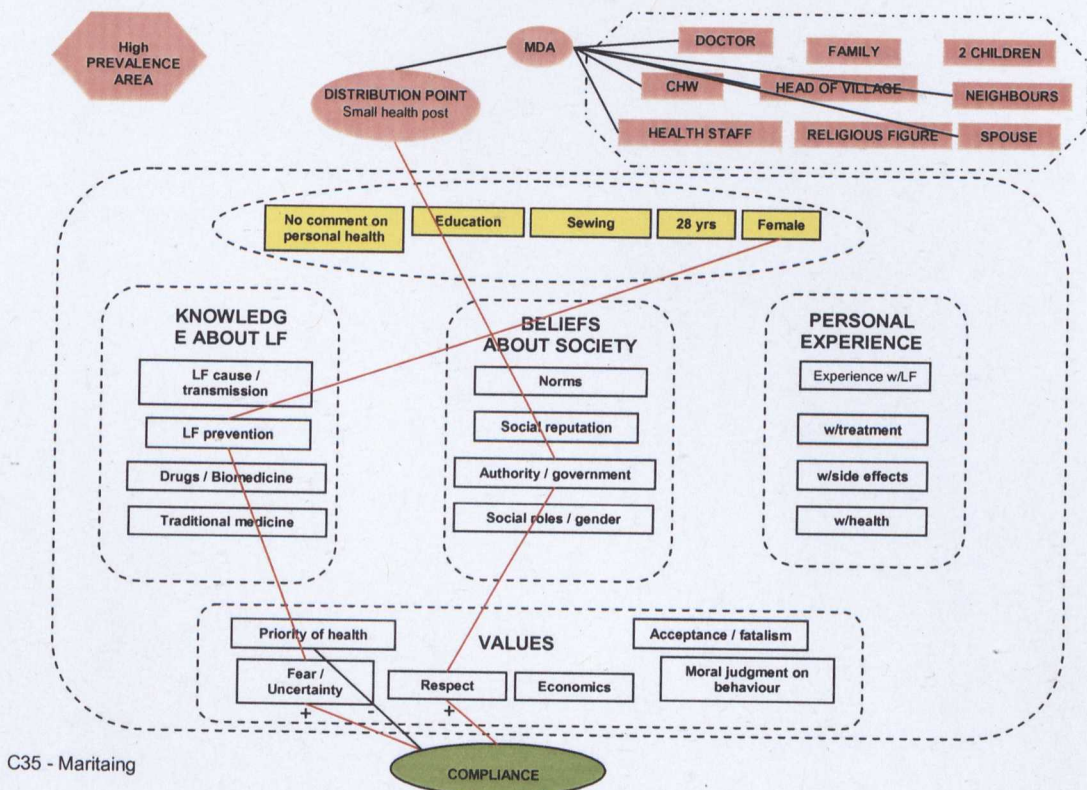
### A complying women from Maritaing (C35)

This woman was a young housewife (28 years old) with two children who had attended sewing school. She lived in Maritaing, the capital of a sub-district in the eastern part of Alor. Maritaing has cases of *W. bancrofti* infection, primarily manifested with hydrocele in men. In fact, this woman claimed that her husband



had *boa besar* or hydrocele. She knew that the disease affected men and boys; however she was unclear how women might be affected.

This woman complied with the treatment while her husband did not. In fact he was someone who tried to influence others not to comply as well. She went to the small health post (*Posyandu*) to pick up the drugs herself – the doctor was there as were other community members. There was water already prepared so that people could take the tablets directly in front of the doctor and the rest of the community. She took the tablets home however and took them after going first to her neighbours for further explanation. She also told me in the interview that they were ordered to take the tablets (illustrated by the red line from distribution point – authority/government – respect – compliance).



She told me of her own personal fear of getting LF, especially since she was a woman. She was afraid of how the disease might manifest itself in women (illustrated by the red line from female – LF prevention – fear/uncertainty – compliance). Considering her earlier statements that the disease affects boys and

men and her own husband's experience with hydrocele, her fear and uncertainty are understandable – how might this disease affect women?

She offered only one comment about other influences on compliance which were evident in her community. She thought that the non-compliers might have had negative thinking and as a result, they do not want to take care of themselves (illustrated by a black line from priority of health – compliance).

## **PATTERNS OF DECISION-MAKING SEEN IN THIS COHORT OF RESPONDENTS**

In the 21 causal chain maps for compliance, some patterns of decision-making were visible. (See Appendix A.10 for other maps.) The complete causal chains (red lines) went through the following groups of themes (note that an individual may have more than one complete causal chain and may go through more than one category of factor on the red route):

- 2 through disease environment
- 4 through personal experience
- 5 through knowledge about LF
- 7 through personal health
- 10 through beliefs about society
- 17 through values
  - 8 through respect
  - 6 through economics
  - 4 through fear
  - 2 through moral judgment
  - 1 through priority of health

In reviewing this summary, only two people (C19 and NC22) in the cohort had a complete causal chain which began with the disease environment where they lived. This finding challenges my initial hypothesis that endemicity would have a strong influence on compliance. I initially thought that people living in highly endemic areas would be more willing to comply with treatment while those living

in areas with no disease would be less likely to comply. This was based on my assumption that people living in endemic areas would better understand their own risk for infection. While two people did attribute their reasons for compliance to disease environment, there was only one other mention of it (in the black routes): one woman (C57) living in Kalabahi said that she took the tablet even though she knew that she had no risk for the disease because of the area where she lived. This suggests, as her causal map shows, that there were other factors influencing her decision. In her case, fear and respect for authority and government were the motivating factors. It is possible, in addition to other more important influencing factors, that people have a difficult time estimating their personal level of risk as associated to the disease environment.

Only four individuals based their compliance on factors on the right side of the map: personal experience with treatment, side effects or the health system. All four (NC22; NC26; C41; NC48) reported experiences with side effects which negatively affected their decision to comply; from watching their children's or their spouse's side effects, their neighbour's or their own family's. This confirms experiences which have been seen in other parts of Indonesia (section 1.4.) where early elimination campaigns failed because individuals threatened health workers after having negative experiences with adverse reactions associated with LF treatment. In the campaign in Alor, we concentrated our efforts to counter this historical record by providing information about side effects prior to treatment and ensuring that health staff was present in highly endemic areas the first night after the MDA to reassure villagers in the event of adverse reactions.<sup>98</sup> In this group of four individuals, one man (NC22) did not receive any information from the community health worker, whose opinion he did not respect anyway. Furthermore, the woman (NC48) who witnessed the side effects in her husband and children reported that when the community health worker distributed the drugs, she did not explain anything about the disease or the drug. These two individuals did not receive any prior information about possible side effects. The

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<sup>98</sup> This was the gold standard which was established during the pilot project in 6 villages (see Krentel et al 2006) and it did alleviate the fears of villagers during that first round of treatment. I am unable to say, however, if the District Health Authority continued this practice in subsequent rounds of MDA.

other respondents were swayed by observations of others regardless of prior knowledge about the possibility of side effects: one woman (C41) told me that if her neighbours had told her that they had many adverse reactions, then she would not have taken it and; one man from Fanating (NC26) observed his wife's side effects and refused to comply.

Within this cohort, 5 individuals based their decision to comply on factors related to their knowledge of the disease on the left side of the map. This pattern confirms the earlier findings on knowledge of aetiology and transmission of disease (section 5.2.1.) where individuals seemed in general to have a multiple and varied understanding of cause of disease, most often vague in biomedical terms. In fact two of the individuals who had red routes through the cluster of themes called "knowledge of LF" (NC50; NC51) spoke about their reason not to comply with biomedical treatment due to their adherence to traditional medicine which they relied on as a protective measure against LF. The remaining three (C5; C10; C35) complied with treatment because of their belief that the drug would prevent disease. As a result, only three individuals chose to comply because of their knowledge of the drug's preventive qualities. This further supports the theoretical basis for my research which suggests that traditional health promotion theories that are rooted on an individual's biomedical knowledge as a pre-cursor to behaviour do not correctly predict the influences which pervade an individual's reasons to comply with LF treatment.

There were 7 individuals who made decisions on compliance based on their present health status. This was, in some ways, an unexpected result of the survey and I did not specifically ask about personal health during the interview. With the exception of one woman, (NC12) whose condition contraindicated her from taking the treatment (breastfeeding), 5 other individuals did not take the treatment based on their good health or personal health maintenance. One woman (NC39) was sick at the time of treatment, so she did not receive the treatment; that was her initial reason given for not complying. However, she added that after feeling better, she still did not want to take the tablets since she was healthy and not sick and could work. For her, sick or healthy, her health status negatively affected her

compliance. Two people, a man from Kalabahi (NC22) and a man from Mausemong (C38) both reported that their personal health was good so therefore they saw no reason to comply with the treatment. Interestingly, living in an endemic area (Mausemong) or a non-endemic area (Kalabahi) did not affect their decision not to comply. There were two men (NC50; NC51) who both reported regular use of traditional medicine as a way of maintaining their health and preventing disease. This tradition in Alor involves boiling papaya leaves and drinking the water afterwards. This bitter tasting drink is reported, by these two men, to keep them healthy. Only one man, a civil servant from Kalabahi (C5) explained that his health at the moment was good, but if he did not take treatment, then he would face shame in the company of his office if he had lymphoedema of the leg. He added later that if this happened, where would he get the money to pay for a costly operation? His good personal health and his desire to maintain it had a positive effect on his compliance.

Complete causal chains for 10 individuals went through the centre group of factors – beliefs about society (norms, social reputation, authority/government, social roles/gender). For the maps of these 10 individuals, there are a total of 14 complete causal chains. The majority (8) of the complete causal chains went through authority; while 4 touched norms, 1 went through social roles/gender and 1 through social reputation. We looked at each of these themes in depth in the earlier sections and we saw that beliefs about society were usually associated with factors which were not related to the disease or the drug. Rather, these societal factors were often associated with perceived consequences and benefits of complying or non-complying behaviour such as: achieving a good social reputation (C5), satisfying one's social role as a man and provider by staying healthy (C5), being a good leader by fulfilling responsibilities to provide a positive example to the rest of the community (C30; C38), respecting orders from authority figures (C35) or following the norm of conformity (C10; C15; C19). Interestingly, the black lines representing the perceived influences present in the community also included societal factors, specifically: 10 through norms, 8 through authority and 3 through social roles. Not only did some respondents

experience influence from the society around them, but respondents also perceived this to be an important influence for others.

For 17 individuals, complete causal chains included values: priority of health, fear or uncertainty, respect, economics, acceptance or fatalism and moral judgment on behaviour. These values were derived from the interviews themselves. 8 of these complete causal chains included respect. 6 of these chains included links between respect and authority which had a positive influence on compliance (C10; C15; C35; C38; C55; C57). As stated in the earlier sections of power and hierarchy, people in Alor in general have a considerable respect for authority – whether it is the village leader, head of the household or the Regent of the district. The complete causal chains for these 6 individuals shows how respect for authority can increase compliance in individuals. One person's (C41) causal chain linked the community health worker and neighbours to respect – these links also had a positive effect on compliance. Only one man (NC50) had a negative effect on compliance linked from respect. His respect and use of traditional medicines had a negative impact on his compliance with the LF treatment.

A fairly large number of complete causal chains<sup>99</sup> (6) featured economic considerations. The links to economics were varied: personal health (C5; NC39), social roles (C5), spouse (NC13), priority of health (NC16) and occupation (NC28). The influence of economics in treatment was not something obvious at the beginning of this research. In fact, the interviews and the map analysis showed the importance of economics as a positive or negative influence. For example, people are sometimes too busy working to seek treatment (NC16; NC28; NC13) and do not want to risk a possible loss of income by seeking treatment during their work hours (negative influences). In addition, if people felt able to work then they did not feel the need to seek treatment (NC39). These negative influences on compliance reflect respondents' primary concerns about their economic stability – losing a day's work would not be an acceptable risk to take for the benefit of the

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<sup>99</sup> In addition the perceived importance of economics (illustrated with the black lines) was also high – with 5 respondents mentioning it as an important influencing factor for others (C10; C19; C30; NC39; NC50). These perceptions had both negative and positive effects on compliance.

treatment. None of these individuals were civil servants or worked in private enterprise – instead they were farmers, housewives and a porter at the harbour and their income would be made on a daily basis. There were also positive influences of compliance which were linked to economics. For C5, the risk of getting LF if he did not take the treatment was too costly for him in economic terms – who would pay for his operation? He also felt responsible for the economic livelihood of his household and if he is sick with LF, then he would not be able to provide for his family.

Four individuals mentioned fear as part of their complete causal chain for compliance. Two of these had positive influences on compliance. For the woman in Maritaing (C35) fear of how the disease manifested itself in women was a strong motivation for her to comply with the treatment; while another woman from Kalabahi remarked how fear of authority made her want to comply with treatment. For a man from Fanating (NC26) and a woman from Kalabahi (NC48), observing the side effects in their respective families produced fear which in turn made them avoid the LF treatment. Fear, as we saw in the early section, is a powerful emotion in Indonesia and so it is not surprising that some individuals were motivated by their fear – either positively or negatively.

As we have seen in an earlier section on social norms (5.4.) as well as in many of the complete causal chains described in these 21 maps, one of the pervasive social norms in LF elimination on Alor included the norm of conformity, meaning in this context, compliance. In order for this norm to be existent, many people throughout the community must be convinced to comply with the treatment (for whatever reason) and do so in such a way that it becomes known to other people. The range of people involved in respondents' decisions to comply with treatment shows that all aspects of the community were involved with the MDA. This range of individuals would help to create an environment for this norm to exist; e.g. where people would either know or perceive that everyone else around them was taking the treatment, so they would be out of place not to do so themselves.

Complete causal chain included the following individuals:

- 3 through family
- 3 through neighbours
- 2 through health staff
- 2 through spouse
- 2 through religious figures
- 1 through children
- 1 through community health workers

Outside influences connected to complete causal chains reflect the holistic approach taken in the MDA campaign. As I have mentioned earlier, in the MDA in Alor, both in the pilot project and in the subsequent district-led campaigns, community leaders (religious, governmental, cultural) were often enlisted to assist with promotion of compliance with the treatment. Of course, the involvement of these leaders would have varied in between villages, but it is certain that the district health staff directing the campaign knew of the importance of their participation. In addition, with the often public nature of the distribution – following church or mosque services, in schools, at health centres – crowds would be drawn to the event and the perception that everyone was complying would be propagated.

Aside from the public nature of the MDA, the closer circle of neighbours and family (including spouses and children) was also important as influencing factors on compliance. These people offer direct experience (both negative and positive) about the treatment. In several cases (NC22; NC26; NC48) observing the side effects in the family was enough to influence some respondents to avoid treatment. Others turned to their neighbours for advice (C41) before taking the treatment. Living proximity to these people (family or neighbours) may affect their credibility and the believability of their experiences with the disease and / or the treatment.



## 5.9.4. CONCLUSIONS DRAWN FROM THE USE OF CAUSAL CHAIN MAPPING

### Conclusions on the utility of causal chain mapping for compliance of LF treatment

In each case (see Appendix A.10. for a presentation of each map), adding up the positive and negative values of the contingent factors on the complete causal chains (red lines) for an individual correctly predicts the respondent's actual behaviour. In those cases where there was more than one complete causal chain, the greater the number of values (positive or negative) is still predictive for behaviour outcome. In fact, the sum of the values is predictive of the outcome of the programme for each individual who has been mapped in this way. This represents one utility of the mapping method – showing the ease with which an individual's outcome of behaviour is revealed through the map's structure.

Another important element of the use of causal chain mapping is that the diagrams focus attention on only a few statements as being crucial to an individual's logic and influence on compliance with LF treatment. These few statements are taken amidst details from pages of transcripts from the individual interviews and once placed in the causal chain map, are linked up and given values to reveal the actual reasons for an individuals' behaviour. Once these themes or factors are placed on the map, the researcher is better able to find relationships among statements which may have not seemed related during the interview. This process allows the richness of the text to be simplified in order to more easily describe the reasons people reported for compliance (complete causal chains seen as the red lines) as well as to reveal their opinions on other factors within their communities which they felt would influence compliance (as illustrated by the black lines). It is important to note that all connections were made only from the respondents' comments which explicitly linked a belief or other factor to compliance, so the degree of interpretation on the part of the researcher was minimized by the mapping process (resulting in a high degree of coder overlap or interrater reliability).

In the 21 maps, each individual only exhibits one or two complete causal chains (red lines) (only two individuals' (C5 and C10) maps revealed more than 3 complete chains). This shows that even though there are many factors which may impinge on individual behaviour and the perceived behaviour of others, only a few of them prove to be fundamental as influences on behaviour. The maps, by illustrating these complete causal chains in a clear and concise manner, reduce the analytic burden on the researcher in this kind of behavioural research. They are able to remark on the presence of other influencing factors (the black lines); however for themselves, they have fairly specific and clear reasons why they chose to comply or not with the treatment (the red lines).

Every map has at least one complete causal chain with either a negative or positive value indicating its influence on compliance. Some individuals' maps revealed that they had more than one complete causal chain indicating that they were persuaded by two or more different sets of factors. Not every map had a black line. In fact, two respondents (NC28; NC29) did not mention any non-personal influences on compliance, thus, their maps showed no black lines at all. Respondents' opinions about other motivations within their communities (black lines) seemed to be varied with the richness of the interview. Where respondents offered more information in the interview in general, there were more opinions about the other possible influences on compliance. However, this does not suggest that maps with few or no black lines were not valuable interviews; merely that some individuals were more vocal and descriptive in their accounts than others. The fact that at least one complete causal chain could always be found also suggests that regardless of the interview quality, a suite of causal factors which is likely to have been responsible for the respondent's behaviour could be identified. At least with respect to its primary objective, the mapping method is robust with respect to interview quality.

Causal chain mapping also shows the effects (positive or negative) that specific factors have on compliance for each individual. These values give the researcher a clear and succinct picture of the relevant influencing factors without some of the detail and complexities which are inherent in the interviews. Although these

complexities are essential to the analysis of the research question – and in fact, considerable attention has been given to each one individually in earlier sections – understanding the effect of these influencing at the individual level can be complicated. The maps allow the researcher the ability to see which factors, at the individual level, take precedence in directing behaviour.

In the previous sections of this chapter, we have looked at each of the themes individually – social norms, coercion, power and hierarchy, aetiology of disease – and how those themes were presented across the data set. What the exploration of those themes did not do however, was investigate how these themes interacted within the individual. Why do side effects have a positive effect on compliance in one individual and a negative effect in another? Or how do these factors affect someone who perceives their health to be good? The maps provide a method of looking at the interaction of the themes at the individual level. And the combination of many individual maps then is able to show if any patterns of decision-making are present in the selected cohort.

### **Thematic conclusions from causal chain mapping**

When taken as a whole cohort of 21 maps, one of the main patterns coming from the research is the strong presence of non-health related factors influencing people's decision-making processes. As we saw in Chapter 3, traditional health promotion theories often root behaviour in knowledge and perception of risk. An examination of these maps shows that in fact, there are many other factors (norms, authority, external influences or economics) which seem to have a more important effect on decision-making. Influence by these factors represents non-health related benefits of compliance with treatment, among them: fitting in with peers (norms), having a good reputation by following authority, protecting yourself from sanctions (following authority), feeling safe, protecting your family, neighbourhood or village from LF by complying with treatment, etc. Health-related benefits, on the other hand, are represented by prevention of disease or cure of an existing condition. Although some people do express this as a primary influence, the majority of the respondents whose maps we have examined do not

mention this is their primary reason to comply. Their expressed influences are more related to the non-health related benefits of compliance.

Another important thematic conclusion taken from the use of causal chain maps is the ability of the maps to demonstrate new relationships amongst factors as well as dispel earlier hypotheses. For example, the maps demonstrated a lack of real importance living in an endemic area had on an individual's compliance. This was contrary to one of my initial hypothesis at the beginning of the research. In addition, analysis of the maps revealed the importance that economics had at an individual level in determining compliant behaviour. Evaluating the people involved in influencing decision-making revealed a cross-section of individuals – from village leaders to children. This provided a basis of understanding for the creation of the strong norm of conformity which has been described here as well as in earlier sections.

The use of causal chain mapping constitutes an innovative approach to the analysis of discursive interviews. It provides an opportunity to identify in the data those statements of crucial importance to the research question, without isolating them from the context of the individual. Once these statements are placed onto a map, links can be drawn which further reveal influences on behaviour. By analysing the cohort of maps, the researcher is able to draw conclusions and observe patterns which may not be as readily perceived in the thematic evaluation. This provides an opportunity to further generate as well as to check previous hypotheses.

## **CHAPTER 6: DISCUSSION**

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### **6.1 BRIEF REVIEW OF THE RESEARCH AND ITS FINDINGS**

The primary research question for this study relates to the motivations of people living in Alor District, a remote area in eastern Indonesia, to comply with mass drug administration (MDA) towards the elimination of lymphatic filariasis (LF). According to the WHO, a minimum of 80% of individuals living in an area endemic for LF must comply with treatment for LF (Diethylcarbamazine (DEC) and Albendazole) once a year for a period of 4 – 6 years (Ottesen 1985).

Achieving this level of compliance is challenging. Obstacles to compliance with MDA globally have included: adverse reactions after compliance with LF treatment (Putrali et al. 1975; Partono et al. 1979; Partono et al. 1981; Partono and Purnomo 1985; Jain et al. 1986; Babu and Satyanarayana 2003; Babu and Kar 2004; Mathieu et al. 2004), lack of community involvement (Ramaiah et al. 2001) and programmatic issues relating to the supply of drugs (Kasturiratne et al. 2001; Babu and Satyanarayana 2003; Babu and Kar 2004). Factors which have been shown by others to be associated with compliance include higher education levels (Kasturiratne et al. 2001); increased knowledge as a result of health education (Ahorlu et al. 1999; Mathieu et al. 2004); knowledge of positive side effects of Albendazole as an anti-helminth drug (Beau de Rochars et al. 2004); participation of local leaders (Ramaiah et al. 2000); and distribution through kin groups (Katabarwa et al. 2000).

My research has attempted to build on the existing knowledge base to deepen understanding of how known factors impact compliance. The results from the quantitative KAP survey conducted in 2004 in Alor showed 76% of respondents received the drugs (and 96% of those reported swallowing the pills) in the last MDA (in 2004) despite some deficiencies in basic information about LF in terms of transmission and cause of disease. The absence of an association between levels of information and compliance with treatment suggested that other factors

were at work. A small number of open-ended questions included in the survey questionnaire probed influences on compliance, responses to which revealed non-health related areas of influence: emotion (fear in particular), submission and obedience, social norms, personal gain, social acceptance, being a good citizen and care for others. These data suggested deeper motivations determining compliance, apart from mere knowledge about LF and perception of risk.

A comprehensive analysis of the major health promotion theories which might contribute to a conceptual approach to understanding compliance proved somewhat unsatisfactory. Such theories often deal with long term behaviour change, rather than one-time decision making. A number of perspectives proved more fruitful in helping build theory from the interview data. These included norms, self-interest, group membership, strong reciprocity, repeated interactions, emotions as well as reputation formation. These perspectives are also presented as solutions to social dilemmas.

In analysis of the in depth interviews, classification of causes of LF included both endogenous and exogenous categories, that is, respondents saw cause as lying outside of self (for example, deriving from elements of the physical environment; from supernatural forces; and from organisms entering the body); as well as inside the self (for example, stress; over-exertion; and neglect of personal hygiene). Respondents' personal theories of disease (including aetiology, transmission and progression of disease) outlined in Chapter 5 (see table 7) do not appear to predict compliant or non-compliant behaviour. Instead, they seem to play a small role in the complex web of factors which an individual must consider when asked to take the LF treatment.

The Alorese people were able to accommodate, simultaneously, different concepts of causation, a practice that is commonplace in clinical practice. Their beliefs arose from both their own experiences with LF, information from health staff and what they heard about LF from others in their families and villages. Information from health staff was not necessarily wholly believed and a few respondents

mentioned their scepticism with regards to information received through health staff.

There was evidence of respondents' thinking having observed basic epidemiological principles relating to observation and generalisation. For example, respondents were able to link mud and marshy or low lying areas with increased risk for LF. They rarely linked the disease with mosquitoes, though a few did, and a smaller number were familiar with the 'correct' biomedical explanation of the disease, which included both worms and mosquitoes. However, correct knowledge did not appear to be associated with compliance with treatment and beliefs about what causes LF were fairly evenly distributed between those who did and did not take the medication, with the exception of a belief in the supernatural: none of the respondents mentioning black magic as a cause was a complier.

Although lay beliefs about aetiology do not seem to affect compliant behaviour, lay beliefs about the treatment itself seemed to be more influential. Although quantitative comparisons cannot be made in qualitative research, those who complied with treatment more commonly reported perceived benefits to the treatment than did non-compliers, and those who did not comply reported more drawbacks than compliers. Perceived drawbacks of treatment included the possibility of side effects, the high number of pills required and the perceived inability of the drug to cure *kaki gajah*. An unexpected finding was that people perceived the drug as ineffective in reducing lymphoedema and elephantiasis of the leg. Despite efforts to incorporate Geresa Dreyer's management of lymphoedema (Dreyer et al. 2002) into the campaign to reduce long term manifestations, it seems the message had not pervaded the community significantly.

A key finding of this study has been the strength of social norms in Alorese culture. This is not a society characterised by individualism, but rather one in which collective values relating to conformity, obligation and duty exert a powerful influence on members of the society and result in mutuality and

reciprocity of help and support. The effect of these social norms had a strong influence on compliant behaviour. Health was highly valued by community members, and this high valuation of health was in turn related to being economically productive and independent, to being able to support self and family and not having to rely on others to provide for their families and self (and making themselves a burden on the group). Preservation of lineage and contributing to the future of their community were also related to the value placed on health. Membership of the group was another important social norm and compliance with treatment sent a strong message that an individual was responsible to the group and shared its responsibilities (by valuing health and making the government programme a success).

Compliance appeared to have become a social norm in its own right. Conformity in this context meant that respondents took the medication, regardless of their level of understanding about LF or its treatment. To this effect, there was evidence that people may be publicly compliant (collecting the medication or pretending to swallow the pills) but were privately non-compliant (did not take it once returning home or not swallowing the pills). In general however, most people preferred to have compliers as neighbours (see table 10) whether or not they themselves complied.

Social hierarchy, authority and status were pervasive throughout the fabric of society in Alor. Social position determined a person's status, authority and influence. Strong social hierarchies were evident at the level of village, government and neighbourhood. These hierarchical structures with their associated power and authority are ingrained into the Alorese from childhood, in common with the rest of Indonesia. These factors were seen as influencing compliance with LF treatment. People with authority were invited to participate in the MDA in order to use their positions to influence the people to comply. These people were well aware of the power they had to communicate information and disinformation to those below them in the hierarchy – sometimes described as uneducated, simple people tied to their cultural traditions. Another kind of authority mentioned was that of the international organisation or individual. The



perception that services or medication brought from abroad were more advanced and therefore better pervades in some of the comments of respondents.

Furthermore, some people expressed a blind faith in government services as well as a powerlessness to refuse whatever the government ordered. They believed that the government had their best interests in mind. Once preventive or curative services were received through the LF treatment, some expressed gratefulness and appreciation that external forces (God, district health authority, wealthy people or international organisations) cared enough to look after their health, thus saving them money in the future.

Within the household, the traditional hierarchy places the husband at the head of the household. Men perceive themselves to be in this role and as a result, see their health as a priority in the household. While men retain this traditional and often ceremonial role, most of the decision-making and practical actions in the household are carried out by the wife. With regards to responsibility for health in the household, there was evidence of four different models: the men taking the primary role; the woman taking the primary role; joint responsibility and; autonomy of decision-making. Some men used the threat of force to ensure compliance or non-compliance from their wives; while other controlled their wives' access to LF treatment. The tendency on the part of some respondents to refer to joint responsibility between the man and woman for health in the household, or in some cases, total independence and autonomy in decision-making for health reflect the changing nature of gender roles in Alor. While much of Alorrese culture remains rooted in the more traditional, particularly in the rural areas, there are nonetheless signs of it being in the process of transition from a traditional patrilineal society to a more modern egalitarian society where hierarchy is less pronounced.

As almost a partner theme to power, authority and hierarchy, the role of coercion arises as a factor influencing individuals to comply with treatment. Again, use of, and reaction to, forms of coercion also seems to be changing in Alor. Fifteen years ago in Indonesia, the government was a more authoritarian and coercive structure

whose tentacles ran directly from Jakarta down to the smallest village. With the fall of Suharto and the New Order in 1998 and the advent of decentralisation in the early 21<sup>st</sup> century, people at all levels are becoming more empowered. As society continues to shift towards greater openness and education and concern for individual rights increases, the use of coercion may also shift as an effective tool used to influence people. However, as evidenced in this research, for the time-being, it remains an influential factor securing compliance with LF treatment.

Emotions emerge prominently from my data in the context of motivation to comply with LF treatment. The emotions of fear, shame (*“malu”*) and anger are linked most frequently by respondents to LF, its treatment and diagnostics. These three emotions have an important place in an Indonesian and Alorese cultural context and so it is not surprising that they have become intertwined in the provision of treatment for LF and in perceptions of the disease itself. Furthermore, they were shown to have an important influence on compliance. Fear was the most commonly referred to emotional state when discussing compliance with treatment for LF. In view of the important role that shame plays in Alorese and Indonesian culture, I had expected it to be the more prevalent emotion mentioned during the interviews; however it was less frequently mentioned than fear. Shame, particularly, is an emotion experienced in relation to the imagined views of others and not merely the self, and so acts powerfully to maintain and enforce social norms. Positive emotions such as joy, happiness and pride were less often mentioned than negative ones like fear, shame and anger.

## **6.2 LIMITATIONS OF THE DATA**

Since opportunities to observe directly the process of taking the tablets are few (notably only in the school setting where children were obliged to swallow them under the eye of teachers and other onlookers; section 5.2.2.), this study relies on self reported accounts of behaviour. In common with all studies probing personal and private acts, this makes the study susceptible to biases relating to recall and veracity of response. As we have seen (above), MDA is offered once a year for a period of 4-6 years. It is possible that some respondents confused their stories between various years of MDA as, for example, in the case of the man from

Mausemong (NC/C37), whose account contained evidence of recent non-compliance as well as compliance. I made deliberate efforts to limit the possibility of recall bias in both the investigatory KAP survey (which took place in the autumn of 2004, only weeks after the administration of the 3<sup>rd</sup> round of MDA) and in the in-depth interviews, (which were conducted in the autumn of 2005, just weeks and sometimes only days after the most recent round of MDA). Since the MDA was in process when I came to Alor for research, one of my criteria for the selection of villages was that they receive the MDA for 2005 prior to being included for the sample selection. Nevertheless, it is possible that despite my efforts to limit this recall bias, some people still may have confused their stories from previous years. Inconsistencies in individuals' accounts may reflect also other biases, such as a social desirability effect.

Another limitation of this research relates to the generalisability of the findings. The study took place in Alor District, a small area in eastern Indonesia which is different culturally and ethnically to other parts of the country. Indonesia is made up of thousands of islands which stretch across several time zones, include millions of people speaking different dialects and languages and include four practicing religions (Islam, Christianity, Hinduism and Buddhism). There have been major political attempts to knit this culturally diverse country into one national identity, including the introduction of Bahasa Indonesia as the national language, but the nation remains extremely culturally diverse. Given the variations in the Indonesian cultural context, findings from my case study may not necessarily transfer to the whole of Indonesia. Nevertheless, this is not a principal aim of a qualitative study. Moreover, a pre-requisite of successful interventions is a comprehensive understanding of the local context, and so a strong case can be made for carrying out research which enables GPELF campaigns to be specifically targeted to localised settings. Furthermore, the influences on compliant and non-compliant behaviour are fundamental and it could be argued that they are universal concepts. As this is the first study of its kind, investigating the reported influences on compliance, its findings may be important for other LF campaigns and perhaps other infectious disease control programmes. Further research is recommended into the applicability of these universal influences on

compliant and non-compliant behaviour in other contexts and settings. As seen in following section (6.3.), many of these influences are described independently in different settings; however their combined presence as seen in the Alor data warrants further investigation to determine the generalisability of these findings for other contexts.

My identity as a foreign Anglo-Saxon woman could have also contributed to limitations in data collection and analysis, as could my comprehension of the Indonesian language, Bahasa. I was aware of this possibility at the outset of the data collection and tried to minimise it by using an Indonesian PhD student (a man and fluent English speaker) to accompany me and to conduct the in-depth interviews while I observed<sup>100</sup>. To my surprise, at times I found people more ready to converse with me as an outsider than they were with him, an outsider to Alor, but an insider in Indonesia. His dress and demeanour as a university-educated person as well as his unfamiliarity with Alor at times appeared to influence respondents. I was told that people mistook him for a government worker, which could create fear and apprehension due to the historical events of the New Order period. After a couple of interviews, I was advised to introduce him as my Bahasa tutor in order to alleviate any fears people may have had. As a result, after the first several interviews, I preferred to take the lead in the interviews, whilst relying on him to assist with translation and contextual interpretation of meanings of words.

Consequently some of the disadvantages I may have had as a foreigner may have also been advantages. Yes, I was an outsider to Alor and Indonesia, but I was also enough of an insider to Alor (I had travelled more throughout the islands than many Alorese and certainly more than most Indonesians<sup>101</sup> and had spent 2 years intermittently working on the Alorese islands) and as a result, some people appeared more willing to converse freely with me without fear of repercussions.

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<sup>100</sup> This was also at the request of my upgrading committee, March 2005.

<sup>101</sup> It was common experience for me, when in Jakarta, to have to draw a map of eastern Indonesia in order to show people where Alor was. This experience is not unique to me and was reported by Kathleen Adams. In her experiences, the Indonesian travel agents she spoke with in Jakarta politely told her she must be confused and thinking of Lombok, a large island east of Bali. Adams, K. M. (2004). "The genesis of touristic imagery." *Tourist Studies* 4(2): 115-135.

Again this probably was a reflection of their apprehensions which arose during the events of 1965 and the New Order period as much as, if not more, than their perception of me as less of an outsider than my research assistant.

Another area where my identity may have limited the data collection was in reference to gender. When interviewing men, for example, it was useful to let my male research assistant take the initial lead in introducing the interview process and me, and then I would continue on with the interview, after he had invited me to. As seen in the earlier chapter discussing gender in Alor, women's power is less seen at the household level, where the father retains the ceremonial position as head of household. Because of my previous 2 years of experience working on Alor, I was aware of this and therefore wanted the interview to be respectful of the man's position within his household. It is possible that in some interviews with men, however, I received a more public account of their actions (Green and Thorogood 2004), then I did with women, where it was to my advantage to take the interview on my own, without the research assistant present. In those cases, there was easily more familiarity in the discussion, and in some cases, we both sat on the floor and chatted more freely without the bounds of a formal interview. As a woman, however, my unmarried and childless status, created a social difference between us. These are two life events which define identity in the culture<sup>102</sup> and gain respect.

Finally, as I have observed throughout the PhD, Alor is in a state of transition where aspects of the traditional patrilineal and agricultural society are still present, but where increased exposure to media and to development has influenced norms and contributed to slow societal shifts in concept like gender and government authority. As a result, my reporting of results from interviews conducted in 2005 may not reveal the entirety of the picture of Alor today in 2007. Nevertheless, this research provides a snapshot of the situation as it was observed and reported by me and offers some insight into motivations influencing people to comply with LF treatment. Some of these themes are broad enough to be almost universal – such

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<sup>102</sup> In Indonesian and Alorese meetings, when asked to introduce yourself, you are almost always asked to say if you are married and how many children you have.

as gender, power and hierarchy, coercion and emotions. So despite potential shifts in society within the last two years, I would argue with some certainty, that these themes would still play a strong contributory role.

### **6.3 THE FINDINGS IN CONTEXT**

The principle findings of this research suggest that primarily non-health related factors influence the people of Alor to comply with treatment for LF. Contrary to current theories within the field of health promotion, biomedical understanding of disease and perception of risk appear to have less weight on the decision to comply or not to comply with treatment. Themes such as social norms, authority and hierarchy, coercion and fear seem to have principally influenced the decision-making process of these 43 people. There is presently no literature which confirms these themes as influencing factors for compliance or non-compliance with LF treatment. In fact, there is limited research on qualitative investigation in the field of lymphatic filariasis, both globally and in Indonesia. Many of the qualitative studies which have been done concerning LF (Hunter 1975; Bandyopadhyay 1996; Gyapong et al. 1996; Ramu et al. 1996; Ahorlu et al. 1999; Babu and Nayak 2003a; Babu and Nayak 2003b; Wynd et al. 2007a; Wynd et al. 2007b) have dealt with burden of disease, cost of illness and identifying knowledge and socio-cultural aspects of the disease, rather than investigating individual influences on compliance with treatment. Despite calls for increased research into the motivations of compliance in order to improve the long-term uptake of LF medication across populations (Malecela-Lazaro and Twum-Danso 2004) there has been little research devoted to this area.

In Chapter 2, I describe the health promotion models with widest currency, most of which assume that a person's perception of personal susceptibility to risk of infection is necessary before any change in behaviour is enacted. As part of the topic guide used in the interviews, I asked each respondent where they believed LF came from, what caused it, what happens when you get the disease and who is most likely to be at risk for infection – in order to get a better understanding of respondents' perception of their own risk of disease. Respondents characterised factors causing disease ranging from those under their individual control

(behaviour-related to hygiene and cleanliness) to those beyond their control (environmental, hereditary, inherent susceptibilities, supernatural causes). A similar range of themes was found by Andrea Caprara (1998) in her ethnographical studies of peoples in Côte d'Ivoire and Bahia, Brazil. She found that interpretations of contagion and prevention "cut across five main relationships: empirical and analogical thinking, symbolic factors and social organization, the concept of person and body elements, natural and supernatural powers and individual and contextual factors." (page 996) (Caprara 1998) She found that there was not a general theory of contagion, but rather it was a multidimensional concept which involved society and culture. The data from Alor tend to corroborate these findings – I found mixed interpretations of disease causation involving factors which the individual could or could not control. Both studies show the complexities of cultural interpretations of contagion when compared with western biomedical theories which involve contact with contagion and the body's response. This finding is also echoed in earlier research by Rory Williams (1983). In his study of elderly Aberdonians, he found that respondents elaborate "quite complex aetiologies, often including social factors and personal behaviour as components" (page 189) (Williams 1983).

In the data from Alor, the concepts of "*darah manis*" and "*darah pahit*"<sup>103</sup> were described by several respondents as explaining the inherent susceptibility an individual has to disease in general (including LF). If your blood is sweet, there is little you can do to prevent the fact that you are indeed at greater risk of infection than your peer who may have bitter blood and who is therefore stronger in fighting infection. Similar concepts were found by Mildred Blaxter (1983) in her study of Scottish middle-aged women. As in my Alor study, this inherent susceptibility (Blaxter calls it individual susceptibility) was distinct from hereditary disease and involved an "inborn or inherent weakness" (page 65). Some people in her study were described as being more susceptible to disease than others, although this did not mean that they were unhealthy, rather that "they were more 'open' to disease from the time they were born" (page 65) (Blaxter 1983). Williams (1983) described a related finding when respondents described "centres

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<sup>103</sup> Sweet blood and bitter blood

of weakness in a person's constitution" (page 191) where disease or symptoms collected at different times during a person's life. When looking at perception of risk for disease, these concepts of individual or inherent susceptibility or centres of weakness affect an individual's acceptance of disease as something beyond their control. According to this view, there is certain inevitability about infection – regardless of what one does to prevent it – the body's constitution is such that one will eventually succumb to the disease. This mentality of fatality or resignation to infection with disease would certainly affect an individual's interpretation of campaigns which promote changing behaviour or preventive behaviours as risk reduction strategies for disease. People with weak constitutions may see themselves at permanent risk for infection and as a result, may perceive any preventive behaviour as futile in the face of their inherent bodily condition.

Another of the main findings on aetiology is echoed in Mildred Blaxter's work (1983). She writes (page 68), "...general models of causal processes, painstakingly derived from their experience as they saw it, were often scientifically wrong in detail, but were not in principle unscientific." In a similar fashion, respondents in Alor do not think of cause scientifically or in biomedical terms, however; they apply rational thought based on their own observations and experience to their theories of causation of disease, which in of itself is the basis for the development of scientific theory. For example, respondents often described LF as coming from contact with rice fields or wet swamplands, rather than from mosquitoes or caused by worms. (Similar findings in India and Papua New Guinea showed respondents did not know about the transmission cycle (Rath et al. 2006; Wynd et al. 2007b).) Their perception of the environment as playing an important role in causation is indeed correct, despite the fact that their interpretation of the epidemiology of the disease could be considered as flawed from a strictly biomedical standpoint. However, respondents instead depict a simple epidemiology which understands the clustering of disease around rice fields and in communities. By making the link between disease and rice fields or swamps, respondents demonstrate that rational thought and understanding, based on experience, is prevalent and forms the basis for their beliefs. This is not unlike the epidemiological studies which, for example, show a link between the herpes



type 2 virus and cervical cancer. In addition to the simple link between agent and disease, there is also a link with the virus, sexual behaviour and poverty thus confounding the idea that a single agent causes disease (Tesh 1988). In the Alorese data, we see an understanding of environmental and behavioural factors, combined with inherent susceptibility and sometimes the disease agent itself, demonstrating a complex understanding of the transmission of disease.

The strength of social norms within the Alorese communities was one of the important findings of this research. Their importance is worth looking at within the context of the Theory of Community Organisation whereby community participation and methods promote ownership of ideas in the community. The sense of conformity, community and belonging identified in the Alorese data links with Rissel's (1994) idea stating that psychological empowerment is enhanced by a sense of community. The empowerment of the individual and the community are intertwined. Furthermore, Paulo Freire's concept of "conscientization" or critical consciousness which comes from a social analysis of conditions and people's role in changing those conditions (Minkler and Wallerstein 1997), implies awareness in the community in order for collective critical thinking and analysis to occur. This awareness may be nothing more than acceptance of present circumstances; however for conscientization to occur, communication to the community would be essential. It is difficult to assume that communities can have an increased consciousness without some catalyst, internal or external, and without some degree of communication between community members. In the Alorese data, social norms around the act of compliance with treatment were, in some cases, first introduced by health staff into the community – either directly or through local authority figures. These initial contacts may have been the catalyst which began the conscientization of the community to understand that they held the power to influence the health situation within their villages.

Compliance with LF treatment could be described as a social norm within some of the accounts from Alor. To this effect, people wanted to ensure that their neighbours and families saw them comply with treatment. This was particularly true in situations where the MDA was public and people were asked to comply

directly in front of health staff. In some cases, there was evidence of public compliance and private non-compliance. Within this context, insights into how individuals managed the presentation of self are likely to be relevant. Erving Goffman wrote "... when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which it is in his interests to convey" (page 4) (Goffman 1959). Goffman seems to explain precisely what occurs in those accounts where individuals publicly accepted the treatment, while privately discarding it.

The concept of power and hierarchy was another theme shown to have impacted compliance at the individual level. As observed throughout this dissertation, hierarchy is an important part of the social structures in Alor as well as in Indonesia. The people who exist at the top of this hierarchical chain – village leaders, religious figures, government officials – embody Weber's description of authority and domination (traditional, charismatic and rational/legal) (Chalcraft 2007). Rational-legal authority is based on legality and contractual establishments. In Alor, those with rational-legal authority are civil servants, teachers, doctors and members of the health staff as well as village chiefs. The second kind of authority he describes is traditional authority which is based on the idea of the "eternal yesterday" meaning that this is the way that things have always been done so we continue to do them. Authority is received from others in a higher position or may be inherited. In my data, traditional authority figures would be cultural and community leaders like village chiefs. And finally charismatic leaders tend to maintain their authority because of their virtues (ethical, heroic or religious).

In Alor, we saw examples of how religious leaders used their moral and religious authority to stress the importance of the MDA. Of course, as Weber notes, mixtures of kinds of authority are seen in real circumstances rather than only the pure forms I have described above. In Alor, for example, some village chiefs maintain their rational-legal authority invested in them by the government while at the same time they may also have charismatic authority (because of their knowledge of black magic or white magic) or they may have traditional authority (their father was head of the village before them). (Coser 1977) Charismatic

authority is familiar throughout the history of Indonesia. President Sukarno for example, the first president of Indonesia, possessed Weber's description of charismatic authority – combining power derived from the supernatural in Javanese and Hindu traditions with the immense responsibility to restore social order after independence from Dutch colonial rule. Not only did he perceive himself as a charismatic ruler, but the Indonesian people did as well. (Legge 2003)

Moreover, Weber believed that authority was characteristic of the relationship between the leader and the follower, rather than the features of the leader alone (Coser 1977). We are able to see how the leaders in Alor are perceived by examining how those who were lower in the social hierarchy (displaying a subordinate or a “serf mentality”) saw themselves in respect to authority. Some respondents categorised themselves as little or common people, who were less knowledgeable than those in power (either governmental or financial). Whether as little people or people with dirty blood, these people were in positions where challenging authority may not have been a choice. This self-perception signalled helplessness where some people sat and waited for services to be brought to them, rather than proactively searching them out. As a result, they followed the recommendations of those further up the social hierarchy, believing that their elevated position allowed them access to more information and knowledge. As Weber believed, the interaction described in this relationship between leaders and followers effectively depicts the qualities inherent in authority.

I describe earlier how people in authority are aware of their power to influence those below them in the social hierarchy. In a similar manner, those who are lower on the social hierarchy respond to the recommendations and coercion from people in authority because they trust them, have no power to refuse them or because they simply follow it as the social norm. The use of power to achieve compliance has been confirmed in other reports from Indonesia as well as from India and Papua New Guinea. In a study from West Flores, Indonesia, “motivated persons” (page 370) including the local school teachers and the village chief, were responsible for distributing the DEC tablets to the heads of families: “each head of the family was responsible for treating members of his family” (page 370)

(Partono et al. 1984). This programme included three important authority figures at the village level: village heads, school teachers and male heads of households. Enacting this programme of weekly DEC distribution was effective as evidenced in the decline of microfilaria rates and adenolymphangitis. However, the programme began to fail in one area due to two factors – the influx of new residents who were microfilaraemic and the failure of the new village chief to enact the programme policy of giving a full course of treatment to new residents<sup>104</sup>. In the end, the success or failure of this programme hinged on the participation of the person with the highest authority in the village – the village chief. In a study from Tamil Nadu, India, Ramaiah et al. (2001) described the different caste groups living in the study population where the main groups (those who are not socially and economically disadvantaged) dominated the decision-making process in the village. In the delivery programme outlined in this paper, community leaders selected the drug distributors. Programme evaluators found that the community leadership was less committed and active in drug distribution than had been expected. Their motivations, according to health workers, were more concerned with politics and business than with welfare activities at the village level. As a result, those areas that used community directed distribution (Com-DT) had lower distribution and compliance rates than those areas where health services were responsible for distribution. Another reason for failure in the Com-DT villages was that people lacked confidence in the competence of fellow community members to distribute the drugs. (Ramaiah et al. 2001) This study shows both the importance of the engagement of community leaders in the programme as well as the community's response to the knowledge of authority (in this case health staff) rather than that of their peers.

In other research using Com-DT in Ghana, Gyapong et al. (2001) showed the value of using communities and their leaders in MDA. In those communities which were responsible for planning, drug distribution and monitoring activities, success was significantly better (73.8% received and swallowed the tablets versus

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<sup>104</sup> The previous village chief died and the new village chief was apparently not aware of the control regulations in place in the study village. Partono, F. (1984). "Filariasis in Indonesia: clinical manifestations and basic concepts of treatment and control." Transactions of the Royal Society of Tropical Medicine and Hygiene 78(1): 9-12.

49.2%) than in the health services-directed arm (Gyapong et al. 2001). The people chosen as distributors by the community were teachers, retired civil servants and ex-service men as well as some farmers. Furthermore, younger people who were able to read and write were also asked to participate and assist the elders who were busy with the MDA. They were described as people who “had a good character” (page 81) (Gyapong et al. 2001). These people fulfil similar criteria as members of authority and have respect within their village, as were also seen in the Alor data. Their good character and acceptance by the community stands out in contrast to the experience cited by Ramaiah et al. (2001) above. By using community leaders and other respected individuals in their communities, the Ghanaian study allowed the communities to generate their own social norm of compliance.

Similarly, in Papua New Guinea, community leaders maintain a strong influence on the MDA as Wynd et al (2007) recounts:

While traditional hierarchical community structure persist with power for decision making residing with a limited number of traditional leaders, drug distribution programmes may remain successful despite different understandings of LF in affected communities. To date, the Misima campaign has relied very heavily on the assumption that by working through local traditional decision making structures, compliance will remain high. (page 6) (Wynd et al. 2007a)

At the household level, the hierarchy of the husband and wife were also seen to have an impact on compliance with LF treatment as well as with decision-making relating to health. The data showed that there were four models present for decision-making for health within the couple. Among them were: the husband or wife taking full responsibility for health in the household, joint responsibility of husband and wife and finally, autonomy. As the purposes of this research were not to delve into gender relations *per se*, reasons for the occurrence of these four different models were not explicitly explored. Beegle et al (2001) however, offer some insight into decision-making for reproductive health at the household level, which may be applicable to the Alor data. The authors determine that separate ownership of assets, education, social status of the woman and the education

levels of the fathers (woman's father and her father-in-law) contribute to the woman's ability to make decisions in regards to her reproductive health. (Beegle et al. 2001) These factors may also offer an explanation as to why there are four models in the Alorese data for decision-making in relation to health in the household; particularly when considering the status women have once their bride price has been paid in *mokos*. The status of women and their influence on health in the household has also been documented in relation to infant and child mortality in West Java (Widayatun 1991).

In Alor, the woman's primary role is to take care of the household needs, including those of the husband and children. Utomo in her look at gender in Indonesia wrote that "women's *noble role* in Indonesia connotes to their function as wives and mothers...women are obliged to place family as their first priority" (page 2) (Utomo 2004). While this is a traditional role as seen in Alor as well as in Utomo's research, there was also evidence of joint responsibility and autonomy in decision-making in some of the Alorese accounts. I attributed this to the ongoing development of the district and the increased influence of modernisation. Utomo (2004) reported a similar finding in her research among the urban middle-class in Jakarta. She believed that changes in social norms regarding a women's role in the household demonstrated a preferential shift towards "a more egalitarian and co-provider marriage" (page 24) within the group she studied. While Utomo's research cohort represents a more educated and culturally different group (Javanese) than the Alorese, I believe Utomo describes a national trend, applicable also to Alor, as the whole of Indonesia continues to recover from the legacy of Suharto's New Order and its socialisation of gender roles as well as experiences the rise of consumerism and modernisation. These trends are likely to continue as well; particularly with the increasing availability of education across Indonesia for women. As Beegle et al (2001) write, education is a "means of developing 'modern skills,' and a woman who has acquired such skills may use them to argue for adopting modern behaviors in daily life" (page 137) (Beegle et al. 2001). Furthermore, as Dr. František Kratochvíl (the University of Leiden) told me, younger Alorese women are delaying or avoiding entrance into marriage because of their increased education, empowerment and modernity.

The presence of coercion was seen as part of the culture during the New Order era in Indonesia as well as in certain public health programmes, like family planning. Since the end of the Suharto's New Order era, there has been a significant reduction in the perceived power of the military in terms of their involvement in civil service and in development programmes. Moreover, with the recent decentralisation of the Indonesian government, the concept of the strong central government's power reaching into each Indonesian village is no longer as obvious as it was 20 years ago.

Nevertheless, in remote places such as Alor, the idea of a strong government with authoritarian overtones remains in the collective memory – for the people as well as for the leaders and people in the health services. Some of the methods described in this section may seem extensively coercive; however it is important to understand that Indonesians and Alorese have lived in a system which could be described as coercive for most of their adult lives. Richard Coker writes about the cultural divide between the acceptance of coercive measures for TB control in the United States versus Britain and the rest of Europe stating that measures which were seen as acceptable in the US would have never been allowed in the public health strategies in Europe. He writes that “it is important to gain a cultural appreciation of what is viewed as coercive (and what is not) and an understanding of societal context and the perceived need for such measures.” (page 24) (Coker 2000)

Coercion – ranging from persuasion to more overt forms – was reported by respondents in the LF campaign in Alor. Evidence of its use in other LF campaigns in Indonesia was described by F. Partono, Purnomo et al. (1984) in his study in West Flores. He writes (emphasis is mine):

Both health education and community participation were slow and difficult to achieve, demanding continuous efforts of persuasion and sometimes requiring *strong measures* to encourage the villagers to achieve the goals that had been set. (page 372)

Partono et al. do not explicitly state what “strong measures” were used, but his choice of words does not conjure up images of group discussions on the benefits of compliance. Nevertheless, these techniques were successful to a certain extent. “Gradually, people realized the benefits of their control measures and developed faith in the programme and in their abilities to cope with simple health problems in the communities” (page 372) (Partono et al. 1984).

Fehr and Gächter (2002) writing about altruistic punishment, highlight many of the themes which were seen to be influential for compliance: group norms, coercion and negative emotions. In their study, they record human cooperation between non-related individuals, which is not explained by other theories of cooperation like kin selection, reciprocal altruism or indirect reciprocity. They studied the interactions of 240 undergraduate students in Zurich in a series of experiments to judge their cooperation with people who they did not know in investment on a public good. Those who participated were able to punish free-riders or people who minimally cooperated, but at a detriment to themselves and for a benefit to others (thus called altruistic punishment). In their results, the authors found that in order to avoid punishment, subjects cooperated in investing in the public good according to the group norm. In addition, they found cooperation increased over time when the punishment condition was present and decreased when the condition was removed. The threat of punishment was equally important in motivating cooperation. The authors tested the hypothesis that negative emotions, like anger, would be a significant motivation for subjects to cooperate. In fact, subjects recorded “much anger” (page 139) towards free-riders from those who had cooperated. As well, the free-rider anticipated even greater anger because of his non-cooperation than was actually expressed. (Fehr and Gächter 2002)

If I were to replace the above word “cooperation” in their account with “compliance” and “public good” with “treatment with LF”, I believe that Fehr and Gächter’s 2002 study chimes well with some of the primary factors influencing respondents in Alor to participate in the MDA. Negative emotions were seen to be influential – namely fear and anger. The group norm as reflected in the accounts



of many respondents was to comply with treatment; so much so that people wanted to live next door to compliers, regardless of their own personal decision to comply or not to comply. Furthermore, threats of punishment were also important motivators as well as were other forms of coercion. Finally, the more invested someone was with the public good in Fehr and Gächter's 2002 study, the more angry they were at people who were free-riders. In several accounts of community health workers, we witnessed how angry they were at people who refused to comply. These CHW would have been heavily invested in the provision of the public good; they would have given their time and energy to the MDA, understood the value of a high compliance rate in reducing disease as well as received monetary incentives for each person that accepted treatment from them. Refusal of the public good by an individual would cause harm both to themselves as individuals (economically) as well as to the rest of the community (epidemiologically). The threats and anger issued by CHW may or may not be altruistic, especially since they stand to gain with payment for compliers; however there would be, one assumes, a negative effect on their own reputations within the village should they be seen to be yelling and angry.

Although Fehr and Gächter (2002) tested the presence of the negative emotion of anger, the respondents in Alor mentioned fear primarily as a motivating factor for cooperation and compliance. The concept of fear, as highlighted in the scene setting section (5.8.1.), is rooted in Indonesian society at the village level and was also a major part of the strategy Suharto used to maintain power during the New Order period. As a result, it is not surprising that fear is one of the negative emotions affecting compliance in Indonesia. Does fear exist in other parts of the world as connected to MDA for LF? In two papers by Babu et al. (2003, 2004), fear is listed as a motivating factor for non-compliance in two regions in India. In particular, fear of side effects was considered in both studies to be a major factor inhibiting compliance. In East Godavari district, 12% of those who took the treatment reported some kind of side effects (Babu and Satyanarayana 2003) and in Orissa state, newspapers exaggerated the reports of side effects, even attributing deaths to the MDA (Babu and Kar 2004). In both cases, fear was an influential

negative emotion inhibiting compliance. In the Alorese case study, fear is also seen in the context of fear of disease as well as side effects.

## **6.4 IMPLICATIONS FOR PUBLIC HEALTH**

### **6.4.1. A THEORETICAL SHIFT?**

Presently the use of COMBI is recommended for social mobilisation prior to mass drug administration. This programme combines a social marketing approach for health and a communication intervention for behavioural impact. Its theoretical basis for behaviour change hinges on an acronym “HIC-DARM” which translates as “Hear about the new behaviour; Informed about it; Convinced it is worthwhile; Decision to do something about our conviction; Action on the new behaviour; Re-confirmation that our action was a good one; Maintain the behaviour” (page 17) (Parks and Lloyd 2004). Despite its use in different parts of the world and continued research into its effectiveness, a recent study from India revealed that even with an enhanced COMBI approach, non-compliance (37-49%) remained a serious concern (Ramaiah et al. 2006). Why does an enhanced social mobilisation campaign targeting individuals with additional funds from international donors fail to reach adequate compliance rates?

As we have seen, COMBI as well as campaigns rooted in traditional health promotion theories based on knowledge and perception of risk do not always achieve sufficient compliance rates needed for LF elimination. One reason for this may be that these theories tend to concentrate on the individual level, failing to acknowledge the impact of the larger social group on the individual. LF treatment is a free good – it is available to all eligible persons living in a certain area at no cost. However, it is also a public good: in order to receive its full benefit, a significant proportion of the population must take the drug. If not, then the public good will have little or no societal or individual benefit (in fact it will be a drain on societal resources) as both the individual and society will be inherently affected by the compliance or non-compliance of others. Once understood, the temptation to free-ride on the compliance of others would be a risk for every individual; until

they understand the benefits of cooperation<sup>105</sup>. Considering the Alorese data, the theories of human cooperation (Fehr and Gächter 2002) and the solutions to social dilemmas (Kollock 1998) provide an accurate description of the attitudes and behaviours behind individual motivations for compliance with MDA since they include the influence of the group on the individual. While of course some people are influenced by their own personal reasons, most of those in the Alorese study reported influences which were linked to their group. These aspects have never been explored within the concept of MDA for LF elimination.

The inclusion of more group oriented theories does not mean that traditional IEC campaigns and COMBI do not produce valuable results; in fact their theoretical tenets of promoting awareness may stimulate cooperation in the group. Some of the elements described in Babu and Satyanarayana (2003), for example, are individually related to cooperation; such as people in hierarchical structures making repeated contact with members of the community through door-to-door canvassing thus providing a certain degree of interpersonal pressure (Babu and Satyanarayana 2003). And simple messages repeated in communities in the lead-up to drug administration can enhance compliance with treatment as a social norm within the group. Furthermore, there is an ethical need to provide information to people about the LF drugs, their potential adverse reactions and their benefits. Traditional IEC campaigns and COMBI do fulfil these ethical obligations.

If indeed theories relating to groups and enhancing cooperation amongst individuals can be appropriately applied to the MDA programme in lieu of or in tandem with individual behavioural change theories, then we must be prepared to consider a new approach to the way that programmes are designed and implemented. This is not to say that social dilemmas and their solutions are the panacea for the difficulties of reaching high compliance rates, but they do offer a new, unique and valuable perspective from which to address the present challenges to achieving and maintaining good coverage and compliance.

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<sup>105</sup> It should be noted that most of the Alorese I interviewed did not know they were in a social dilemma *per se* and so therefore were not necessarily tempted by the desire to free-ride, although many did recognise the value of cooperation with others in compliance with treatment to prevent disease in their community.

#### **6.4.2. USE OF LAY KNOWLEDGE**

Some of the lay concepts of causation lend themselves more readily to individual preventive intervention than others. Some risk factors would be relatively easy for people to modify, including those relating to hygiene, working hard or climbing trees. However, as we have seen, many of the risk factors mentioned by the Alorese people relate to exogenous causation, and so lie beyond an individual's control. Certainly this applies to those relating to the supernatural, hereditary and inherent susceptibilities, but it also applies to factors relating to area of residence and nature of employment, since for most people, there is little possibility of altering their situation.

The fact that a belief in more than one cause was held simultaneously by many respondents can be seen to have positive implications for compliance with LF treatment. Despite some people seeing the cause as lying in phenomena which were outside of their personal control, many Alorese people nevertheless believed in the power of the treatment to cure the disease. Only supernatural forces were seen to lie outside the control of modern medicine; drugs were seen as impotent by those who believed LF to be the result of black magic, and this is something that clearly needs to be addressed in preventive campaigns. For the most part, however, the Alorese people were able to accommodate a belief in the effectiveness of drug treatment alongside their concepts of causation, even where these did not subscribe to biomedical principles.

Some of the lay perceptions of treatment have implications for information giving. The fact that the drug treatment was seen as having limitations for some, that is, for example, it did not improve the chronic manifestations of the disease, signals a need to impart information to this effect in order not to lead to false expectations. The message that people with chronic manifestations may not experience a reduction in their symptoms after treatment should be conveyed to all those targeted in the MDA. This does indeed present a challenge, as a clarification to this effect can be complicated (involving discussion of calcified worms, secondary bacterial infection, etc.) and every effort should be made to find a simple explanation.

Some of the findings in this study in relation to perceptions of aetiology and compliance may appear counter-intuitive. Most of the health belief models incorporate the notion that understanding risk behaviour and the means by which it might be reduced are fundamental to preventive action. Yet there is no evidence in this study, from the patterning of responses relating to concepts of causation amongst compliers and non-compliers, to suggest that correct knowledge about causes, routes of transmission and the nature of LF is a prerequisite to compliance, despite being a key component of health belief models (Nutbeam and Harris 2004). Moreover, many individuals receive the correct information about LF from their doctor or health workers, yet some remain reluctant to accept this as truth. Although it is important to consider personal theories of disease causation, in this instance they did not appear to predict behaviour. I would propose in fact, that they are only a small part of the complex web of factors which an individual considers when he or she is confronted with a health-related decision. This is apparent when we look at more of those factors and how they interact together in the individual.

The evidence is that although the Alorese people may not be thinking scientifically in strictly biomedical terms, in many cases they do develop theories of disease based on their own observations and experience. There is a simple epidemiology which understands the clustering of disease around rice fields and in communities. The transmission cycle of LF is complex and lay people cannot be expected to fully grasp the intricacies of the worm and mosquito stages of infection. However, by showing they have made the link between disease and rice fields, respondents demonstrate rational thought and understanding. In terms of prevention, the findings may be interpreted as supporting the case for increasing knowledge about modes of transmission of filariasis. If more people were aware of the causes and the routes of transmission, this could result in more people using, for example, insecticides and bed nets, which in turn would have positive outcomes for other insect borne diseases. These simple attempts at epidemiological thinking could be harnessed in future campaigns to encourage certain preventive actions.

Based on the research in Alor, it has become clear that knowledge and risk perception are not necessarily connected to compliant behaviour. In fact, the majority of respondents maintain complex aetiologies of disease and only sometimes amalgamate biomedical explanations into their knowledge systems. The trend in developing countries is to understand better these socio-cultural definitions and understanding of disease. Focus group discussions, KAPB surveys and in depth interviews abound in the literature as a preface to socialisation and education campaigns. However, once this information is gathered, what happens? As seen in Wynd et al (2007), in order “to achieve sustainable improvements in health, efforts to bridge the gap between local health knowledge systems and western biomedical models will become increasingly important” (page 6). Once these cultural interpretations of disease are discovered, it seems they are often reported and then discarded in lieu of communication of the true biomedical meaning of cause and transmission. Rather than abandon it, we should embrace this local knowledge and maximise its use. Blaxter (1983) offers concrete recommendations for the use of lay theories in health. Although she writes about the doctor and patient relationship in the surgery, her words are equally valid for disease control programmes (emphasis is mine):

In the surgery, the doctor’s view of the disease process must be reconciled with the patient’s. The diagnosis must make sense in terms of the patient’s models or *it will not be accepted*. It is assumed, in medical practice, that there is a partial equilibrium between formal medical taxonomy and the informal folk knowledge of the group. Formal knowledge, with time, diffuses and becomes standard, and traditional: conversely, some of the lay accumulated wisdom contains insights and clues which the medical profession can use, and *systematise into formal knowledge*.” (page 69)

Although Blaxter does not give details about how she would prescribe using this lay knowledge, her recommendations are important for public health planners working. One suggestion of how lay knowledge could be transformed into a public health message comes directly from a community leader who was one of my respondents. He recommended telling people that if they took the pills, then

their descendants would be free from the disease. He made this suggestion because he knew the importance of descendants and ancestry within Alorese culture. He was also playing on people's beliefs that the disease is passed down through the family line. His message is bio-medically correct – if everyone takes it, then the disease *will be eliminated* and future generations *will not suffer* from the disease. In fact we used a similar message in the Alorese campaign “Any child born at the start of the campaign will be free from LF.” What we failed to do, and where this community leader had better insight, was to personalise the message so it would impact the maximum number of persons in his community.

Public health programmes tend to stress the importance of understanding and knowledge in addition to awareness-raising as pre-requisites to behaviour change or action. Indeed, most social mobilisation and IEC campaigns start with the development of printed materials which explain the transmission of the disease, its cause, and so on. While I would argue awareness-raising is important as part of inculcating compliance into the community mind as a norm, my research findings suggest that imparting detailed biomedical knowledge itself might perhaps deserve less concentrated efforts. The Alorese data suggests that much of this well-intentioned information does not become internalised by its intended audiences. For example, when I think of anti-smoking campaigns in the West, I am reminded of images of blackened lungs, statements of male impotence and harm to an unborn foetus. If I had to take a KAP survey questionnaire or partake in an in-depth interview asking me why those lungs were blackened or why men became impotent, I would be unable to answer correctly and would be considered as someone with poor knowledge by the researcher. However further research would show that my behaviour as a non-smoker confirms that I was influenced by something to have stopped smoking, despite my lack of intricate knowledge of cause of disease. When considering the often complicated transmission cycles of infectious diseases – with multiple hosts and phases of development – it can be difficult to translate them into simple terms. And is a full understanding of aetiology really necessary if someone grasps the simple fact that mosquitoes bring LF or that the treatment offered prevents and cures disease? As Sylvia Tesh notes, “effective disease prevention can occur without knowledge of the agent” (page

65) (Tesh 1988). The Alorese data shows most of those who were interviewed did not have even basic information on the causal agent; yet they complied with treatment. The data shows that this sample of individuals is motivated by other factors beyond knowledge and perception of risk. Their behaviour is moulded more by social norms, pressure from ascendant individuals and by emotions.

This is not to say that information does not play a role in influencing people, as certainly there is evidence where misinformation negatively affected compliance (Babu and Kar 2004). However the evidence from Alor and other public health intervention areas shows that as planners, we should be more selective and careful in the information we choose to transmit to our target audience (integrating local beliefs, perceptions and misconceptions into our messages) rather than adopting an information-only campaign stressing communication of biomedical cause and transmission, with the assumption that people will be motivated by that knowledge alone.

### **6.4.3. MAXIMISING COMPLIANCE AS A SOCIAL NORM**

One of the important influences on behaviour which emerged from the data was conformity to the social norm of compliance. In Chapter 5, respondents spoke of “everyone taking the treatment” or “everyone attending the village office during distribution” alluding to their perception that all those around them must have complied with the treatment which was offered to them. In Alor, many villages organised public drug administration days, where the health and village officials called up the individual names of families and people in the village to come forward, receive the treatment and take it with the prepared water in front of everyone else. This achieved two goals: one, it showed the health worker without a doubt that the person complied and; two, it showed everyone else in the village or neighbourhood who was watching that the person complied as well.

Success in harnessing compliance to social norms relating to conformity, obligation and belonging (to the group) seem to have been key factors in achieving the high rates of coverage and compliance in Alor. People expressed their felt responsibility for preventing the disease from entering their households,



their village and indeed Alor as a whole, and obligation to other community members, to the health workers and to the government. For many Alorese people, compliance seems to be driven more by a need to adhere to social norms rather than by a full cognitive understanding of the aetiology and transmission dynamics of the disease. For others (such as those who identified their group as being similarly at risk for infection) the social norm to comply would have merged with their understanding of prevention of the spread of disease within their group (herd immunity).

In the context of MDA, conformity can be a valuable aid in achieving compliance. But given its strength, it could also act against efforts to encourage compliance. The strengths of social norms towards conformity could, should the social norms be unfavourable towards compliance, be detrimental to efforts to encourage compliance. Before social norms such as conformity, obligation and responsibility can be used to underpin an intervention, an important preliminary task is to create social norms which support and are favourable to compliance with treatment. So whilst we might conclude from the data that it might not be necessary for information, education and communicational activities to inculcate in individuals all the scientific and biomedical knowledge relating to aetiology and nature of disease, it is essential to convey messages and transmit information which will emphasise the value of compliance with treatment. A cautionary note however should be made regarding the use of the rational health belief models. In a society such as Alor, it may not be essential to observe to the finest detail, all of the principles of these models, but rather, the population will need to understand its seriousness and the means of risk reduction, and importantly, the value to them, their families and their community of taking the medication.

Apart from information giving, other aspects of COMBI and general social mobilisation also contribute to the formation of compliance as a social norm by promoting drug taking days, by holding special meetings and by working with people in the power structure within a village or neighbourhood. One of the end points of awareness campaigns, however, should be the establishment of compliance as a social norm, so that people feel obliged to take it so that they fit

in with those around them. In order to do this, it is recommended that MDA days are made very public occasions – with people visualising their neighbours, leaders and family members actually swallow the pills. This is much easier to achieve in smaller rural areas where the arrival of a car into the village is an event in and of itself, than in larger towns and cities where people live more independent and disjointed lives. In those more highly populated areas, however, approaches could be sought which identify the smaller groups people belong to, like neighbourhoods, churches or mosques, schools and offices. Drug distribution can be public and visual in these smaller groups, rather than at a whole population level, which would be easier in a rural village. Door-to-door distribution should be reserved for mopping up activities, e.g. reaching those people who could not be reached during the public MDA.

Finally, public messages should communicate that everyone is taking the medication to reinforce compliance as a social norm. People in authority and celebrities should be seen to comply publicly in rallies or on television. Repetition and familiarity should be emphasised in any campaign to enforce people's awareness levels as well as their perception that this is a community activity in which everyone should, and is participating in.

By establishing compliance as a social norm in people's communities, the mechanisms of cooperative behaviour which are already present in the community can be set into motion – which may include influences such as altruistic punishment, emotions (fear, respect, happiness, etc.) or reputation formation.

Emotions like fear and shame appear to have an important influence on maintaining social norms relating to compliance. For example, the community response to non-compliance was often one of anger and ridicule. Furthermore, emotions are linked with other influencing factors discussed here, including coercion and power. Fear used with coercion as a way of maintaining social norms was seen as having a powerful influence on compliance, but there were also many references to fear of the treatment. (More information disseminated by

health staff and community leaders and positive experiences with treatment from fellow community members could help allay these fears about treatment.)

Since shame is such a strong emotion in Indonesia, there is great potential in harnessing this emotion in attempts to influence compliance when linked with enforcing the social norm to comply. If people began to associate non-compliance with shame in the face of their community and family, they may feel a greater desire to comply with treatment. Furthermore, as we have seen, being sick in Alor involves neighbours and family members assisting financially as well as with time to care for the ill individual. Future campaigns might want to encourage people not to become a burden to their families and neighbours in the future by preventing disease now with a free and easily distributed drug. In addition, it may be effective in some locations to target shame as the resulting emotion when an individual violates the norm of compliance. So whether in relation to shame associated with having the disease or shame at the thought of one's own district or village being tainted with infection, "*malu*" may have a positive influence on compliance.

Any control strategy must be consistent with local culture, including the need to ensure that culturally appropriate emotional responses are used in the campaign. It would be useful within the context of Alor to look at encouraging the positive emotions as well – like pride and happiness. By providing a record of how well Alor was doing in the LF elimination process through maps or other information tools, people may be more motivated to comply in order to ensure that their neighbourhood, village or sub-district was in the forefront of the campaign. This would instil pride in their community as well as an increased sense of safety as they watched the rates of infection decline in their district.

Emotions should be considered as important motivating factors in future attempts to improve or increase compliance rates. Whether used independently or as influences on other factors, their use will strengthen existing efforts.

### **6.4.3. USE OF EXISTING SOCIAL HIERARCHY IN PROMOTING COMPLIANCE**

A consequence of the pervasiveness of hierarchy throughout the fabric of Alorese society is that there are significant possibilities for it to be used for the purpose of influence in the implementation of the MDA. By using the power and influence of leaders, heads of household and government, the elimination programme is able to harness the use of the existing social norm of compliance with authority. People understand their positions in the hierarchy, both leaders and those subordinate to them.

Those in authority recognised their utility to the MDA campaign. They were higher in the social hierarchy due to their knowledge, position or wealth and as a result were free and able to criticise and offer suggestions to the government health services for the improvement of the MDA. These people also had the power to communicate information (and disinformation) to those below them in the hierarchy.

As the social system shifts with increasing development, modernisation and exposure to new ideas, care should be taken to ensure that the programme shifts together with society. Traditional leaders may experience a weakening of their authority for example and so public health agencies should be cautious about exploiting this phenomenon in the context of compliance.

Gender relations and the social hierarchy in the household have the power to affect compliance with LF treatment because they affect decisions taken within the household regarding health. We have seen how men are perceived to be and perceive themselves to be the head of the household and as a result, how their health is seen to be a priority. Descriptions of the drawings showed how the threat of force was used by men to ensure compliance or non-compliance from their wives. In the real-life accounts, some men actually controlled the access their wives had to LF treatment. While these statements showed one perception of a man's place within the household in the context of the LF treatment, there was

also evidence of joint responsibility with women for decision-making regarding health as well as the autonomy of both men and women in terms of decisions regarding compliance. The apparent discrepancies between these two impressions of gender mimic the complexities present in Alor as it transitions from a patriarchal society to a more modern one.

Several insights can be gleaned from the data on gender in Alor and its influence on compliance. First, intervention efforts to encourage compliance need to heed the fact that the natural inclination in Alor society might be to give priority to protecting men's health and so extra efforts may be needed to stress the need for women to remain healthy too and to see their own health as a priority. In circumstances where women's access to treatment may be limited (e.g. the husband does not pick up the drugs), women can be encouraged to act for their own health and the health of their children, as a way of maintaining a healthy family and its future. This concept could also be integrated with men's desire to ensure a healthy lineage. Men can be encouraged to see the health of their wives and children as a priority to accomplish their own goals as head of the household (continuation of lineage, economics) and as a result should make every effort to ensure that their household receives treatment.

Secondly, by saying that men have authority and the ability to use their authority to influence compliance neither diminishes the power of women in Alor nor does it represent the full picture; women are essentially the backbone of the family, taking responsibility for the care of children, much of the planting and harvesting, cooking and cleaning. They probably do, as many of the accounts suggest, also take primary responsibility for the health of the family. While the man remains head of household, it is perhaps the wife who will actually administer the medication to the family ensuring that they all (including the husband) take it correctly. This division of roles is important to incorporate into any campaign attempting to increase compliance in a community. Approaching men without women means that the will may be there to comply, but the drugs will not; approaching women without men means that the drugs will be there, but the will or possibility to take them will not.

Thirdly, women's power is implicit and not overtly recognised in the community or in the household. Yes, they are strong and valued for their ability to work, bear children and bring in a good bride price, but they are not always given an equal share in the voice in the household or in the community for that matter. Men retain the ceremonial title of head of household and occasionally use it to wield the power associated with its status. Men's roles are associated with power and control while women's are more associated with care, responsibility and quiet authority. These distinctions have important implications for health interventions. Programmes need to preserve men's sense of power and not make them feel usurped, while at the same time, acknowledge that women have *de facto* power at the household level and probably are responsible for most health issues.

As Alor's development continues to shift and more people are exposed to new ideas, there will inevitably be a continuation of shifts in the relations between man and woman. These changes will take time however, and for the moment, one can conclude that the relationship between men and women in their respective social positions has the ability to affect how health decisions (including LF treatment) are made within the household.

#### **6.4.5. ENFORCING SOCIAL NORMS AND ENCOURAGING COOPERATION**

The evidence in Alor and in other LF studies in other areas shows the positive effect of certain forms of coercion on compliance. In general, I would argue that promotion of coercion in public health campaigns is rightly seen as abhorrent and contrary to human rights and ethics and I am not suggesting that jail terms or fines are promoted for people who do not comply with LF treatment. I would suggest however, that in societies like our own and in Alor, coercive techniques are used that can be seen to be successful in enhancing healthy behaviour and encouraging cooperation and which are not necessarily seen as unacceptable by the majority of people. The perception may exist that such techniques are no longer used openly in western public health campaigns due to ethical considerations, but I would argue that methods used in large scale interventions that use legislation to secure

cooperation of the few in the interests of the majority are not so dissimilar. Consider the anti-smoking campaign, which in order to be effective in reducing second-hand smoke, must have a high compliance rate amongst smokers. Clean air is the public good to be enjoyed by all, providing that cooperation is significant. Presently, if one is caught smoking in a public place where smoking is now banned, a monetary fine will be issued in most countries. This is an acceptable form of coercion (negative sanctions) which we allow in our societies and has shown produced results.

Allen and Heald (2004) reach similar conclusions in their assessment of the HIV/AIDS epidemics in Uganda and Botswana. Reviewing the contextual and intervention-related factors which may help explain the greater success achieved in Uganda compared with Botswana, where the trend is towards increasing rates of infections, the authors state:

More controversially, we have also argued that social constraint has been a key aspect of what has occurred. It seems to us that human rights activism linked to HIV/AIDS in Botswana has hindered public health measures. Botswana has followed the accepted line in HIV intervention with its stress on voluntarism, confidentiality, gentle persuasion and encouragement. Only now, with the population facing meltdown, are more coercive measures being advocated and even then in the face of intense opposition from outside agencies. In parts of Uganda, on the other hand, sexual-behavioural change has been regulated by local groups, and in some instances violently enforced. It is not our contention that the extreme measures observed in northern Uganda should become a model to be emulated in HIV/AIDS control. However, such events illustrate the point that human behaviour rarely changes because of health education alone. Change is facilitated when information is linked to procedures of compliance. (page 1152) (Allen and Heald 2004)

Allen and Heald witnessed more dramatic coercion (the use of executions in Uganda) in their assessment than the kinds of coercion which were seen in Alor (threats, moral judgment and interpersonal pressure). Similarly in both case studies however, the range of coercive techniques observed in both Alor and Uganda originated from within the community, rather than as directed by external health campaigns. For public health agencies, the challenge is to understand

comprehensively the situation on the ground, so as to take full advantage of these existent techniques in order to encourage better cooperation while at the same time balancing individual human rights and ethical considerations.

This balance of individual human rights and ethical considerations with stronger seemingly coercive measures is expressed in two distinct public health traditions explored by Kirp and Bayer (1992): the containment and control model and the social learning model. The former comes from the classic tradition of public health which developed in the context of the control of epidemic diseases a century ago. This strategy makes greater use of compulsory measures, sometimes even mandating or legislating, as in the case of enforced quarantine, in order to control disease. The latter, the social learning and persuasion model, represents a newer tradition in public health; which is based on cooperation and inclusion, an emphasis on voluntary action and the role of information and education in motivating individuals to protect their own health. (Kirp and Bayer 1992) These traditions respond to different theories of disease causation. The containment and control model addresses the contagion theory which requires that sick people should be kept away from well people; and the social learning model addresses more the recent lifestyle theory of disease which places the individual as the cause of his or her own disease as a result of unhealthy choices (Tesh 1988).

In the Alorese data, both models exist in parallel. Remembering the case of the schoolchildren who were obliged to take the LF drugs in their schoolroom while supervised by both health care personnel and teachers; and in circumstances reported by respondents, where health officials obliged people to take the medication in front of health staff. Both of these measures appear to fit more in the tradition of the containment and control model. In other cases, where the medication was distributed and members of the community were able to take it home and decide for themselves whether to take it and when to take it, after they had been advised to do so by health staff and had been informed of the drug's benefits – these procedures are more line with the social learning and persuasion model.



The question remains as to which elements of each tradition should be drawn upon to eliminate diseases like lymphatic filariasis which require a mass approach? The response is indeed highly context specific. In the West, it is expected that the preference would be for the social learning and persuasion model, which is more in line with a culture where consumer rights, for example, exist within health care delivery. Overall, with some exceptions, classic epidemic control strategies which use more coercive techniques, have been rejected in the West in favour of more liberal approaches, which rely on understanding and informing human behaviour rather than restraining and controlling it.

As we have seen, however, the history of events in Indonesia has to some extent inured the Alorese people to the use of, if not force exactly, then at least what could be described as unnecessary pressure by those outside of the system. For example, it is doubtful whether any parent in a western country would be happy with a situation where their child was obliged to take a certain medication at school with neither prior information sent home concerning this nor a request for parental consent; yet there was no evidence that parents questioned this in Alor. The spirit of cooperation and obligation to the group, and of deference to authority is deeply rooted in the Alorese society and as a result seemed to make people more receptive to more coercive approaches.

A question remains as to whether such coercive approaches used in the past in Alor are likely to be as successful in the future. The shift to a more democratic and empowered way of life has occurred in Indonesia with the fall of the New Order, and Alor has also demonstrated signs of change in its society. It seems reasonable to assume that at least part of the remarkable progress made in Alor in achieving high levels of coverage and compliance of treatment, and thereby control of the disease, is in part attributable to the more coercive measures used. But there are also enough instances of resistance to coercion on the part of many respondents, to be doubtful of its total undisputed efficacy. It seems likely that approaches aimed at encouraging social norms in favour of compliance with treatment contributed at least as significantly to the success of the programme as did the more coercive techniques. These approaches to encourage social norms

included the influence of authority figures as well as the manipulation of emotions associated with compliant behaviour. Some may argue that standard advertising materials have a certain degree of subtle coercion associated with them in that they persuade one to action. In Alor, the advertising materials for the LF campaign stressed the protection of family and future generations – appealing to people’s sense of responsibility and future lineage. I would argue that these forms of persuasion lie outside of the spectrum of coercion as they do not use “power, intimidation or threats” (page 17) (Coker 2000) but rather they appeal to people’s needs and desires.

And finally, could the experience documented in Alor be applicable to other geopolitical contexts? The answer to this question lays in an evaluation of the elements of the public health approaches present in any particular context, for example, the importance society places on individual autonomy; the commitment to personal liberty; and the role of medical knowledge in motivating preventive action. The challenge is to tailor the intervention to a specific historical and cultural context, hence the vital importance of ethnographic research and the considerable involvement of key community persons prior to any campaign in order to properly understand the balance of forces present in a certain context.

#### **6.4.6. NON-FUNCTIONAL BENEFITS AS WELL AS FUNCTIONAL BENEFITS OF COMPLIANCE**

In a further departure from traditional health promotion, health education and social mobilisation, I would suggest that awareness activities for the MDA of LF treatment include the promotion of non-health related benefits of the treatment. Traditionally, awareness campaigns stress the functional benefits of a cure or a treatment – one will heal from sickness or prevent disease. Generally speaking, health itself is seen as the positive goal of preventive campaigns and is often considered to be motivation enough to achieve participation or compliance. However, the research in Alor and Allen and Heald’s research (2004) have shown that the promise of health is often not enough of a motivation. In Alor, the prospect of being cured or preventing LF was infrequently named as the primary reason people complied with treatment. As a result, we would expect future

campaigns based solely on the health benefits of LF treatment to have less beneficial outcomes in terms of compliance. While it is important for people to know about the functional benefits of LF treatment, I would argue that the non-functional benefits of taking the drug should be emphasised.

So what exactly are functional and non-functional benefits? Benefits in general marketing terms refer to “the personal value consumers attach to the product attributes... that is, what consumers think the product or service can do for them” (page 4) (Keller 1993) Functional benefits are the fundamental advantages received when consuming a product or using a service; and are more linked to physiological and safety needs (Keller 1993). Non-functional benefits or symbolic benefits are the extraneous advantages a product or service offers to consumers; corresponding to “underlying needs for social approval or personal expression and outerdirected self-esteem” (page 9) (Keller 1993). In advertising, consumers are informed of the functional capabilities of the brand or product while at the same time, instilling the brand with symbolic values and meanings which are relevant to them (Meenaghan 1995).

The better known a product becomes, the less necessary advertising of their functional benefits is. For example, Coca-Cola has become such a well-known product that it no longer needs to tell consumers about its functional benefits. Its advertisements currently direct the consumer to the well-being and happiness they will enjoy when they have a Coke. Their now-dated slogan “Have a Coke and a Smile” told the consumer nothing of the product’s use or function; rather it sold Coke on the basis that it would make you happy. These motivations represent the non-functional benefits of drinking Coca-Cola – happiness, well-being, acceptance. In fact, in today’s world, Coke would probably have a difficult time selling their product based on its functional benefits – it is a sugary pop drink with caffeine – and the health benefits would surely be disputed. (Personal communication with Carole J. Munro, former Vice-President in Global Marketing for Nestlé Inc.)

In light of these (rudimentary) explanations for functional and non-functional or symbolic benefits and the evidence for Alor, it becomes clearer perhaps why some motivational campaigns do not succeed in increasing compliance rates for LF treatment. They tend to emphasise only the functional benefits of the treatment – getting better, preventing disease or complying with a government programme – rather than including emphasis of the symbolic values of taking the treatment. While these functional benefits may indeed influence some to take the treatment, as we saw in the Alorese data, the symbolic values were often more influential on behaviour. Therefore campaigns should make every effort to emphasise the symbolic values associated with the treatment, like feeling modern by taking chemical medication; being perceived as someone who cares about his family and health; being seen as someone who fits in with everyone else; being a good citizen and following the government programme; being smart and preventing future economic loss; protecting future generations from LF or; feeling safe (because you have prevented disease or you have avoided possible sanctioning from your community or the authorities).

#### **6.4.7. A SOCIETY IN TRANSITION: IMPLICATIONS FOR PROGRAMME PLANNING**

Finally, as we have seen, Alorese society seems to be in a state of transition as it moves towards a modern developed society. As a result, dual approaches may be more appropriate in such situations where multiple societal contexts exist and where society becomes more complex as it balances this shift. For example, the data reveal that while parts of Alor remain steeped in a traditional patrilineal agricultural culture, there is evidence of increasing development as people become more educated, have greater access to media and as transportation increases to and from this remote area. This shift also affects a respect of traditional authority and its coercive techniques. As we saw, evidence of social learning and containment are both present in the data set and exist in parallel in Alor; so a balance between these two approaches would need to evolve with society. Similarly, diversified and changing gender roles are also present in the research with evidence from a traditional male-dominated approach to a modern partnership based on equality. Health interventions which focus their efforts singularly on an uninformed

analysis of the present context risk missing a proportion of the population (either the traditional or the more developed).

Therefore, public health interventions and awareness campaigns should take into consideration the changing face of society, paying heed to the old as well as the new. Interventions need to tailor and target their approaches so that they incorporate the cultural context in which their target population lives, including its varying facets. Wellings et al (2007) make similar recommendations for public health programmes in the field of sexual health. They call on programme planners to consider social norms, the utilisation of existent social networks in society and to address structural determinants like poverty and gender which contribute to risky sexual behaviour. By taking note of complexities present in society, planners will produce comprehensive, multi-level and multi-partner interventions which will be more effective than single-component interventions or general interventions ill adapted to the context for which they are intended (Wellings et al. 2006).

Because of the long term nature of LF MDA campaigns (4-6 years minimum), planners would benefit from better tailored programmes which incorporate the development of social norms in the society where the intervention is planned. By incorporating cultural tenets already in place in society into the intervention, the programme will benefit from continuous internal controls and promotion which do not require additional funding or planning. Neglecting the societal context places the burden of elimination on the health system alone with the inclusion of some key leaders. Due to the difficult nature of achieving compliance for a treatment which is given without diagnosis and to people who are not sick, interventions should include as many existing aspects of society (norms, values and perceptions) as possible in order to increase people's conviction to cooperate and comply with treatment.

These recommendations require a significant shift in thinking away from traditional health promotion and health education to an approach which is rooted in group dynamics as opposed to individual behaviour. In addition, these

recommendations call for a greater inclusion of marketing principles in programme planning and implementation so as to increase the perceived symbolic benefits of treatment. These data from Alor have demonstrated compelling evidence to support such a shift in thinking and supplementary research into operational development of these recommendations would enhance the development of MDA campaigns in the future. While this research has implications for the GPELF, it may also apply to other contexts where mass administrations are used (like immunisations, anti-helminth campaigns) and where the uptake of a public good by the majority of the population is promoted (like clean air from non-smoking or environmental protection).

### 6.6.8. WHAT HAS THIS RESEARCH ADDED TO PUBLIC HEALTH?

- Description of how people are motivated with regards to compliance with LF treatment in a Southeast Asian context.
- Demonstration of the non-functional or symbolic benefits in motivating health behaviour, in particular the elimination of LF.
- Expression of the reduced importance that knowledge about disease, treatment or perception of risk has in influencing compliant behaviour.
- Development of a new method of analysis to work within the Framework analysis (Ritchie et al. 2003).
- Elaboration on the complexities of working within a society in transition.
- Illustration of the importance of tailoring and targeting in MDA campaigns.
- Recommendation for an extensive re-evaluation of the way MDA campaigns are planned, to take into consideration evidence from this research which shows the importance of non-functional benefits as well as the necessity for tailoring and targeting.

This research proposes that a revised approach be taken to preparation and implementation of the MDA for LF elimination; put simply to approach and encourage compliance with MDA as a group phenomenon rather than an individual one. The data in Alor has shown that there are many factors influencing individuals to compliant behaviour which are not necessarily associated with education and information, the bedrocks of present health promotion theories and IEC campaigns. Rather, there seems to be an important contribution of group membership, adherence to social norms, the powerful influence of emotions as well as the non-functional benefits of eliminating LF. These themes are strongly associated with the theory of social dilemmas.

One of the aims of this research is to make recommendations to the global campaign so that compliance with MDA may be improved. Therefore in light of the findings, it is important to consider how they may be translated operationally so that they may be useful for present and future LF MDA campaigns. In depth research conducted in a similar manner to this PhD may be too timely and costly for most MDA campaigns, which are often stretched financially. However it is worth noting that good preparation, although moderately time-consuming, may actually save funds in the long term as MDA campaigns will be appropriately targeted to their communities and may have better results. I suggest here that a modified version of this study be considered; one which is more loosely associated with present day marketing research. It is highly recommended that further research be conducted in order to operationalise the theoretical findings from this PhD, however in the meantime, the following steps could be used:

- 1) It is recommended that campaign planners do so a series of focus group discussions with community members to identify the non-functional benefits of treatment, particularly in advance of the any communication and development of educational materials. Inquiries should also be made into the lay concepts of disease and treatment. These non-functional benefits (for example, economic well-being, being a modern person by taking medication, protecting future generations, being an educated person, etc.) and lay concepts could then be incorporated as the starting point of communication to communities. Straight scientific information should also be included, but it should be simplified and depending on the audience, kept to a minimum. People should associate MDA with some non-functional benefits as well as the functional benefit of LF prevention and or cure.
- 2) Furthermore, a working partnership with community leaders and authority figures is essential. Many valuable and successful examples of this are seen in the literature, however I would suggest that future MDA campaigns take this one step further, allowing these figures to use the mechanisms present within their communities for the establishment and



maintenance of social norms (in particular the establishment of the norm of MDA compliant behaviour).

- 3) This research was conducted in a rural patrilineal community, where the important groups to which people belonged were neighbourhoods and families. In larger urban areas, these groups may not be as important to individuals and may not hold the same power of influence. In principle, the theory of social dilemmas applies to any environment, so the same principles (social norms, emotions, coercion, authority) should apply in rural and urban locations. Therefore, it is recommended in urban environments to conduct locally specific research to identify the smaller groups to which people belong (religious organisations, clubs, university groups, etc.). Once these groups are identified, their working mechanisms and norms can be used to influence compliance.

These points represent a much abbreviated version of this research and further application of the social dilemma theory and its solutions should be researched so that its applications can be made on a larger operational scale.

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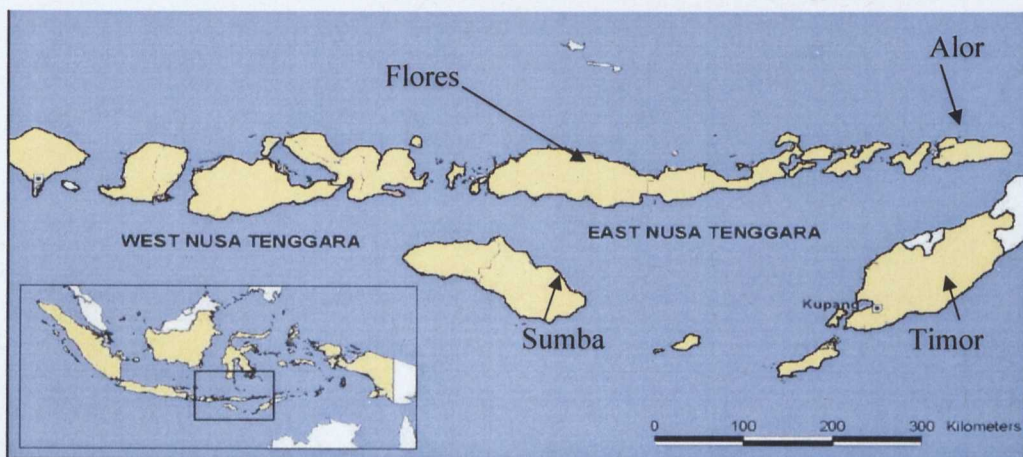
## APPENDICES

### A.1. DESCRIPTION OF THE CONTEXT

Alor is a small district with 13 islands in Nusa Tenggara Timur province. Alor Island is of volcanic origin and on Pantar Island, the last volcanic explosion was in 1992. The terrain is rugged, even the Dutch did not explore inland during colonial times as their horses could not handle the steep terrain in the remote areas. There are over 150 dialects spoken in Alor, some languages spoken only by 300 persons in one village. Bahasa Indonesia is used to communicate in all areas; however some older persons may need translation into local language. The majority of the population are Christian, with 32% of the population practicing Islam. Animism remains prevalent crossing traditional Christian and Muslim religious barriers.

Travel to and from Alor District is difficult. There are a limited number of planes and ferries per week to and from Kalabahi (the district capital). During the wet season (January and February), transportation becomes very difficult and Alor can remain cut off from both air and sea travel.

In general, Alor is one of the poorest districts in Indonesia and as a result the level of education and the level of basic health care in the district are low. In 1998, per capita income in Alor (670.000,- IDR) was 25% of the annual per capita income for Indonesia (2.700.000,- IDR).



Following the results of the health facilities survey and the health seeking behaviour survey conducted by the German Agency for Technical Cooperation, the existing quality of the health services appears to be low in all of the health facilities in the district (Kielmann 2000; Krentel et al. 2006). For example, only 50% of the staff can measure the temperature correctly.



## **A.2. METHODOLOGY FOR THE KAPB SURVEY**

### **A.2.1. THE RESEARCH TOOL**

#### **Design of the KAPB questionnaire**

From 2001 to 2003, I worked in LF control in Alor. During this time, I had previous experience on the administration of a similar KAP survey to the one used in this research. The interview tool used at that time was a fully structured fully scheduled questionnaire which was first developed by me with input and suggestions from the University of Indonesia Parasitology department, a medical anthropologist from the London School of Hygiene and Tropical Medicine and the District Health Authority health officials in Alor. In developing the questions, I also used previous medical anthropological studies on LF carried out by the German Agency for Technical Cooperation (GTZ) in Alor as a guide to assess which questions about LF in Alor communities needed further probing (Setyawati et al. 2002a; Setyawati et al. 2002b). Furthermore, these studies were useful when determining which local terms to use during the survey. The questionnaire also borrowed some questions from previous KAP surveys conducted by the Department of Health Jakarta for LF. For overall health questions in Alor, the research tool modified certain questions from the final evaluation questionnaire developed by AusAid-funded Alor Community Based Health Project (ACBHP) project. Additional questions were added based on discussions with the team as well as following review of the existing literature and “gaps” in existing qualitative information. Following completion of the first draft (in January 2001), the questionnaire was administered twice as a pilot in villages near Kupang and Kalabahi. Changes were made to the survey tool following these pilot sessions in order to improve on its clarity and comprehension.

The same questionnaire was used in the development of a comprehensive mass drug administration pilot project in five villages in Alor District in 2001 (Krentel et al. 2006). A third survey using the same questionnaire was conducted using a reference population of Alor Island to evaluate the 2<sup>nd</sup> round of district administered MDA.

The questionnaire described above had been tested and used in several surveys and provided the framework for the questionnaire used in my PhD research. Since I had participated directly in the design of the original KAP questionnaire, I was also aware of areas which needed improvement and clarification. Several questions were amended to enhance comprehension and an entire section on media awareness and accessibility was removed from the questionnaire, as this information was not relevant to my research.

Because the objectives of my research include exploring motivations of individuals, precise questions needed to be included in the questionnaire to address this aim. Specifically, questions were added about the respondent’s beliefs about the treatment as well as their reasons for complying and for not complying. These were designed as open-ended questions allowing the questionnaire to probe further into reported influences on compliance, and reported motivations for

complying or not complying. I also added a question on whether or not the individual planned to comply in the next round of MDA the following year and the questionnaire probed for reasons for their decision.

The revised questionnaire was pilot tested in a village called Waisika, located an hour's drive outside of Kalabahi. 12 people were interviewed using the new questionnaire and comments were taken on clarity of the language, comprehension of the questions and concepts as well as if and where additional questions were needed to improve the flow of the questionnaire.

### **Data collected**

The questionnaire used in this research included basic demographic information about the respondent (age, education, possessions, occupation, poverty indicators); awareness of LF and its two most common local names (*kaki gajah* – elephant leg and *boa besar* – large fruit); source of information about the disease; perception of the disease as a problem and specification of the type of problem; knowledge about transmission, symptoms and the possibility of LF being asymptomatic; personal experience with someone in the family or oneself having a symptoms like LF and associated treatment seeking behaviour; knowledge, beliefs and experience with treatment of LF (includes question about influence and reasons for compliance/non-compliance); experience and management of adverse reactions; anticipated or intended compliance in next year's MDA; knowledge and practices about prevention of LF.

### **A.2.2. SAMPLING STRATEGY**

The study population in this research was from the island of Alor, rather than from the District of Alor. Because three similar KAP surveys had been conducted in 2001 and 2002 from Alor Island, we decided to use the same reference population from where to select our sample. By using the same reference population in all four surveys, people living on Alor all have the same probability of being selected for the KAP. This allows the three past surveys to be comparable to this present survey. Much of this comparison analysis is outside of the scope of my PhD; however it provided the District Health Authority in Alor with operational data which they could use in their MDA monitoring.

All eligible respondents were selected from Alor Island.

In developing countries, simple random sampling methods are not feasible in many places due to the increased cost in accessing persons in remote villages (Katz and Seger 1994). Additionally, typical sampling frames used in random sampling like telephone numbers or postal codes are not feasible in many developing countries. Most people in Alor do not have landline telephones and postal addresses only apply to people living in the district capital.

Multi stage cluster sampling using a modified Expanded Programme of Immunisation (EPI) method with probability proportional to size (PPS) was used to determine the villages from which respondents would be chosen (Henderson and Sundaresan 1982; Turner et al. 1996; Gyapong et al. 1998). The EPI method is feasible in KAP surveys since the outcomes measured are not rare. Moreover,



the EPI cluster survey technique has been applied to the measurement of coverage levels for other public health programmes, such as MDA and knowledge levels for LF elimination (Turner et al. 1996).

The rationale for this sampling strategy was based on the aim to have a sample which represented the reference population on Alor Island and to which we could generalise the survey results. Because the terrain of Alor is difficult and access to some areas can be impossible during certain seasons, the EPI method of selecting villages with a probability proportional to their size provided a process of random selection which ensured all levels of population density present on Alor were included in the sample.

The sample size was calculated on the following criteria: an anticipated population proportion of 90% with a confidence level of 95% and absolute precision of 5%. The required sample size for these parameters is 138 persons. From the three previous surveys, the intra class correlation coefficient was calculated as 0.235. Using a cluster size of 7, the design effect for this survey is 2.41. As a result, the necessary sample size is 333 persons ( $138 \times 2.41$ ). A buffer of 15% was added in the event of refusals and/or incorrectly administered questionnaires. The total sample size required for the survey was 385 persons, or 55 clusters of 7 respondents. Henderseon and Sundaresan (1982) recommend a minimum of 30 clusters to ensure that the sample has a normal distribution. The basic sampling unit was the household, rather than the individuals in the village.

A list of villages on Alor Island was obtained from the District level Statistics office. According to EPI methodology, villages were chosen randomly from this list so that the sample was proportionate to the reference population, e.g. larger villages and cities would have more respondents in the sample than smaller areas.

Only persons above the age of 15 years were included in the survey as comprehension at this age was expected to be sufficient to respond independently to the survey questions. In addition, chronic manifestations of the disease begin to show at adolescence, so personal experience with LF may begin at this age (Witt and Ottesen 2001). In order to achieve a gender balance in the sample, interviewers were required to randomise for gender so that a near equal proportion would be achieved.

Respondents and households were randomly selected. The interviewers went first to the head of the village to inform them about the survey. The research team had already sent a letter to the village government stating that there would be an upcoming health survey in their village and that although they did not need to inform the community, they could expect an interview team to visit in the coming weeks. After meeting with the head of the village, the interview team went to the centre of the village and, according to the EPI method, threw a pen and began the interviews in the first house in that direction. Upon arriving at the household, the interviewer would introduce themselves and explain briefly about the survey. They would request permission to continue with the random selection procedure. If both sexes above the age of 15 years were present in the household at that time, then the interviewer would flip a coin to choose whether a man or a woman would

be interviewed. If more than one household member of the same sex was present, then the interviewer would choose which person to interview by allocation of random numbers. All respondents were asked for their informed consent before continuing with the interview. If they refused to participate, then the interviewer re-drew another random number and the process continued in the household until someone agreed or all had refused in which case, they would proceed to the next household.

By randomising gender in the manner discussed above, the randomly selected sample provided a nearly equal balance of men and women. Alor remains a primarily traditional society and as a result, heads of the household normally take responsibility for contact with persons from outside of the village and respond to such questionnaires. Despite this cultural expectation, it was important to include women as respondents as well, as the primary caretakers of children, the sick and have the principal agrarian responsibilities in Alorese society.

Only one questionnaire was required per household. After the interview, the interviewer walked to the next occupied house following the initial direction of the pen. If there were no further households present, then the interviewer would return to the centre of the village and re-throw the pen in order to find a new direction.

### **A.2.3. DATA COLLECTION**

A research team of sixteen interviewers were chosen to carry out the questionnaire administration. They were selected after a preliminary meeting, interview and testing period. They came from different institutions in Kalabahi, namely GTZ, the local university, a governmental women's NGO, two local NGO and from a citizen's health advocacy group. These sixteen people (3 women and 13 men) were selected based on or more of the following criteria: they had an interest in health, experience in questionnaire administration, willingness to travel to remote and difficult locations and a higher degree (university). Additionally, these local health organisations due to budgetary constraints rarely have field activities. This survey provided these interviewers with an opportunity to get involved with health care in their district. At the end of the survey, I organised a feedback meeting with the District Health Authority so that they could directly express their opinions of the LF campaign and their impressions about the survey.

A training session was held for two days and the interviewers were briefed on: general information on LF, the questionnaire, methods of asking questions, process for sampling the respondents at the village and household levels and supervised role plays on questionnaire administration. Interviewers were paid an honorarium for each day worked, the two day training and for their travel and accommodation expenses. All interviewers signed a contract with me and a document which waived any liability for me or the funding agencies should there be any accidents during the course of the research. Interviewers worked in teams of two persons.

All respondents chosen to be interviewed after randomisation were given a chance to refuse the interview. They were informed that the results were anonymous and

confidential and they were asked to sign an informed consent form on the questionnaire showing their agreement to participate. They were not asked to write their names on the questionnaire and if they were unable to write, then a simple 'X' or mark was written in lieu of a signature. Interviews were conducted in the household in a location convenient to the respondent. If other persons were present in the same room at the beginning of the interview, the interviewer was instructed to politely ask them to leave. If that was not possible, the interviewer would record on the questionnaire who was present and if any disturbance was caused.

The interviewer administered the questionnaire by reading out each question and recording the answers directly onto the questionnaire. Some questions were prompted, however most were not. It is indicated on the questionnaire where prompting is allowed.

#### **A.2.4. FACTORS ENHANCING AND HINDERING THE ADMINISTRATION OF THE KAPB SURVEY**

Specific factors enhanced the administration of the KAPB survey in Alor. The government of Alor and the District Health Authority knew me and because we had worked together in the past, they gave me *carte blanche* to go wherever I needed to go. Because of my past employment with GTZ, I received logistical assistance from their team in Alor. In practical terms, this meant that I had a reliable driver who was able to manage the often difficult terrain present in Alor, access to their office equipment and support staff, as well as their data and research on health in Alor.

The difficult terrain on Alor was one of the hindering factors in my research. On one particular occasion, we had to back the car slowly down a ridge as the road to one of our randomly selected villages had deteriorated, leaving us less than a meter on either side before a drop of 100 metres on both sides. I deemed that 7 respondents were not worth the lives of the team in the car. Thankfully, upon our return to Kalabahi, we discovered that there was another route to this same village, so a team was quickly dispatched to interview 7 people.

One of the criteria for the choice of interviewers was their willingness and ability to travel to remote places. I accompanied one team to one of the most remote villages we had randomly selected, Mataru Barat. We drove for about 2 ½ hours on a combination of paved and unpaved roads, and then walked for 2 ½ hours to reach this village which sits in the dip of a ridge. When we reached the top, the village was not full of people as many had gone to the fields. Because we would not have time to come back to this village, we interviewed those people who were in the village, selecting the households according to the process described earlier. I should note that the sun rises and sets at 6, and because Alor is not far from the equator, this does not vary much during the course of the year. We were limited to walking in the daylight hours, thus we had to continue with the survey despite the fact that some people were gone to their fields. Upon returning to the site where we had left the car, we found that the children had played with one of the tires and had let the air during our absence.

Another hindering factor to the KAP survey was the heritage in Alor of war and fighting between different kin groups. The difficult terrain in Alor has long protected small groups of people from their enemy neighbours. Small hamlets are tucked into mountains and on ridges in the central mountainous part of Alor. One such village, Kuneman, was skipped altogether by our interview team. As they planned to walk up to the area, they were warned by village elders in the village where they spent the night that there was intense fighting going on and that they would not be safe entering this village at this time. The military police had been called from Kalabahi, but they had yet to arrive to quell the violence. The team decided that in the interest of safety they would need to skip these 7 interviews.

In another of the villages we visited, Taman Mataru, while the team went out to find 7 respondents, the village leaders informed me that there was a considerable measles outbreak ongoing in that village. Twenty children were presently ill and around 12 children had died in the last six weeks. The MMR vaccine was not available in Alor and during the course of a KAP survey in 2001 I had also come upon a mumps outbreak. When outbreaks of a serious nature such as measles are ongoing in the village and children are dying, it is a difficult task to enter a house to ask questions about another less threatening disease and then not be able to offer any assistance to the real crisis at hand. We did however, upon leaving the village, immediately report the situation to the District Health Authority for action. The number of deaths rose in that area, so much so that it made the national newspaper, the Jakarta Post. After that, international agencies such as Médecins sans Frontières became involved in providing measles vaccinations in Alor.

### **A.2.5. ANALYSIS**

Data were double entered into Epi Info 6 by two data entry staff and the data set was validated to control for entry errors. The final data set was transferred to Stata 8.1 for further statistical analysis.

The primary measure of effect used to describe the results was the odds ratio and prevalence was also reported. The outcome variable of interest is self-reported compliance with LF treatment. The exposure variables used for the analysis include: awareness of the disease, knowledge, residence (urban/rural), expressed influence on compliance, source of information about LF, other risk reduction behaviour, perception of disease, perception of susceptibility, intention to comply with MDA next year, external and internal motivations. Interpretation of open-ended questions included coding between myself and another person for inter-rater reliability.

### **A.2.6. REFERENCES**

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### A.2.7. KAPB QUESTIONNAIRE

*Questionnaire for KAP Survey Survey for Knowledge,  
Attitudes and Behaviour in the community  
in Alor District September 2004*

(INFORMED CONSENT)

Good morning/afternoon/evening.

We are from a interview team that is doing a survey together with the Health Authority in the District of Alor, GTZ SISKES, the London School of Hygiene and Tropical Medicine, which is funded by Liverpool School of Tropical Medicine, GlaxoSmithKline and the Parkes Foundation.

We are doing some research on health. This survey is about knowledge, attitude and behaviour of the community about health. Because of this, we would like to ask your permission to discuss a little with us. The interview should only take about 30 minutes. We will not ask your name for this interview. If you do not want to participate, your rights will not be affected in any way.

Thank you for your help.

Signature of the respondent: \_\_\_\_\_

IDNO	
Date of the interview	
Name of the interviewer	
Length of the interview (if possible)	
Location of the interview	
Result of the interview	
1. Interview finished	
2. Interview was not finished because: _____	
3. Respondent refused because: _____	

## Demographic information

### A. IDENTITY

1. How old are you? : \_\_\_\_\_ years

**IF THE RESPONDENT DOES NOT KNOW THEIR AGE, THEN ASK FOR AGE IN DATE/MONTH/YEAR: \_\_\_\_\_ dd/mm/yyyy**

2. Sex : a. male b. female

3. What is your address?

RT/RW \_\_\_\_\_

Compound (Dusun) \_\_\_\_\_

Village \_\_\_\_\_

Sub-district \_\_\_\_\_

4. What is the last class that you completed?

**CIRCLE THE LAST LEVEL COMPLETED.**

	Class					
a. No school	0					
b. Primary (SD / SR)	1	2	3	4	5	6
c. Junior high	1	2	3			
d. High school	1	2	3			
e. University/Academy	1	2	3			

5. What is your religion?

- a. Islam  
b. Christian  
c. Hindu  
d. Other. \_\_\_\_\_

6. Do you possess one or more of the following **(CIRCLE ALL THAT APPLY)**:

- a. Radio  
b. TV  
c. Pig or pigs  
d. Chickens  
e. Motorbike  
f. Bicycle  
g. Boat  
h. Metal roof

7. What is your **primary** occupation?

- a. No work  
b. Agriculture  
c. Housewife  
d. Labourer  
e. Trader  
f. Civil servant  
g. Private

h. Military/Police

i. Other \_\_\_\_\_

8. What kind of house does your family live in?

a. Bamboo or "bebak" walls

b. House with "half" concrete walls

c. House with concrete walls

d. Other \_\_\_\_\_

9. What is your source of water? **(MARK ALL THAT APPLY)**

a. Well without cement

b. Well with cement

c. Pipe

d. Hand pump (in good condition)

e. River

f. Other \_\_\_\_\_

10. Where do you usually defecate? **(DO NOT READ ANSWERS AND MARK ALL THAT APPLY)**

a. Latrine without concrete ("with drum")

b. Latrine with concrete ("swan neck")

c. Shore

d. Garden

e. Field/bush

f. Other \_\_\_\_\_

11. Have you ever heard about the disease Filaria?

a. Yes ⇨⇨⇨ What is it?

b. No

12. Have you heard of "Kaki Gajah?"

a. Yes ⇨⇨⇨ What is it?

b. No

13. Have you heard of "Boa besar?"

a. Yes ⇨⇨⇨ What is it?

b. No



⇒⇒⇒ IF QUESTION #11, #12 AND #13 ARE ALL ANSWERED NO,  
THEN GO TO QUESTION # 40  
⇒⇒⇒ IF ONLY ONE IS MARKED 'YES' THEN GO TO QUESTION # 15

14. Is there a difference between Filariasis, *Kaki Gajah* and *Boa besar*? (USE  
THE  
APPROPRIATE TERMS THAT THE PERSON KNOWS FROM #11, 12,  
13)

- a. Yes ⇒⇒⇒ GO TO QUESTION # 14B
- b. No
- c. Don't know

14B. What difference?

15. Is there another name for the disease filaria:

- a. Yes (such as \_\_\_\_\_)
- b. No, there is not.

16. Where did you learn about filariasis/*Kaki Gajah/Boa Besar* disease? (DO  
NOT

READ ANSWERS AND MARK ALL ANSWERS THAT APPLY. YOU  
CAN

PROVE ONCE WITH: IS THERE ANYWHERE ELSE?)

- a. Heard from the CHW / volunteer drug distributor
- b. Heard from the head of the village
- c. Heard from the health personnel
- d. Read a book
- e. Saw a poster
- f. A friend/neighbour/family member told me about it
- g. Saw a film
- h. Read a brochure
- i. Saw a sticker
- j. Other \_\_\_\_\_

17. In your opinion, is filariasis/*Kaki Gajah/Boas Besar* a problem? (YOU CAN  
EXPLAIN: A PERSONAL OR AN ENVIRONMENTAL PROBLEM)

- a. Yes ⇒⇒⇒ GO TO QUESTION # 17B
- b. No
- c. Don't know

17B. Why is it a problem? (PROBE UNTIL THERE ARE NO  
MORE  
ANSWERS LEFT)

18. In your opinion, what causes filariasis/*Kaki Gajah/Boa Besar*? **(DO NOT READ OUT ANSWERS AND MARK ALL THAT APPLY)**

- a. Germs
- b. Worms in the blood
- c. Curse / Black magic
- d. Hard work
- e. Mosquito
- f. Don't Know
- g. Other \_\_\_\_\_

19. Is filariasis/*Kaki Gajah/Bos Besar* transmissible? **(IF THE RESPONDENT DOES NOT UNDERSTAND THE QUESTION, THEN TRY WITH: Can the Filarial germ move from person to person?)**

- a. Yes
- b. No
- c. Don't know

20. How could you get filariasis/*Kaki Gajah/Boa Besar*? **(DO NOT READ OUT THE ANSWERS AND MARK ALL THAT APPLY)**

- a. Wild or domestic animal
- b. Mosquito
- c. Mud
- d. Don't keep clean
- e. Other \_\_\_\_\_

21. Who do you think could get filariasis/*Kaki Gajah/Boa Besar*?  
**PROBE: WHY DO YOU THINK THIS PERSON CAN GET IT?**

22. What are the symptoms or signs of filariasis/*Kaki Gajah/Boa Besar* disease? **(DON'T READ THE ANSWERS AND MARK ALL ANSWERS THAT APPLY.)**

- a. Fever or "hot" repeatedly
- b. Lymphadenitis in inguinal nodes (Enlargement and painful reddish lump at the inguinal area)
- c. Hard rope-like on the inner side of the arm
- d. Swelling in the leg / foot
- e. Swelling in the genital area
- f. Swelling in the groin / under arm area
- g. Breast feels heavy
- h. Abscess
- i. Urine like milk
- j. No symptoms at all
- k. Don't know at all
- l. Other

**IF THE RESPONDENT DOESN'T KNOW AT ALL OR SAYS  
THAT THERE ARE NO SYMPTOMS AT ALL, GO TO Q #27**

23. In your opinion, do you think that someone can have filariasis / *Kaki Gajah* / *Boa Besar* and not have any symptoms?

- a. Yes
- b. No
- c. Don't know

24. **Within the last 2 weeks**, has there been any family member suffering from one or more of the symptoms in number 22?

- a. Yes, \_\_\_\_\_ persons.

What symptoms? **(REFER TO QUESTION # 22 FOR SYMPTOMS)**

- b. No ⇒⇒⇒ **GO TO QUESTION # 27**

25. Did you seek help for this (these) symptoms?

- a. Yes
- b. No ⇒⇒⇒ **GO TO QUESTION # 27**

26. From where or from who did you/your family seek help when your family member was suffering from the symptom(s)? **(DO NOT READ THE ANSWERS**

**AND**

**MARK AS MANY AS POSSIBLE)**

- a. Servant of God
- b. Puskesmas
- c. Pustu
- d. Polindes
- e. Kader/TPP
- f. Traditional healer
- g. Friend / Neighbour / Family member
- h. Accept it as fate and do not treat at all
- i. Other \_\_\_\_\_

27. Can filariasis/*Kaki Gajah*/*Boa Besar* disease be treated?

- a. Yes
- b. No, but you can prevent it ⇒⇒⇒ **GO TO QUESTION # 30**
- c. No ⇒⇒⇒ **GO TO QUESTION # 38**
- d. Don't know ⇒⇒⇒ **GO TO QUESTION # 38**



28. How is filaria disease treated? ⇒(YOU CAN PROBE ONCE WITH:  
"IS THAT ALL?"

29. Why do you think someone would want to take treatment for filaria?  
(PROBE:WHY? PROBE UNTIL THE PERSON DOES NOT HAVE  
ANY MORE REASONS. FOR EXAMPLE, ASK: ANY OTHER  
REASONS? IS THAT ALL?)

30. Have you ever been treated for filariasis?

a. Yes



30A. When were you treated?

(month/year) \_\_\_\_\_

(WRITE THE LAST YEAR ONLY)

30B. What did you receive?

a. Pills or tablets ⇒⇒GO TO #30C

b. Syringe ⇒⇒GO TO #38

c. Don't know ⇒⇒GO TO #38

d. Other \_\_\_\_\_ ⇒⇒GO TO  
#38

(IF THE RESPONDENT PICKS 2  
ANSWERS (a + other), THEN  
CONTINUE WITH a. ONLY.)

30C. How many pills were you given?

30D. How were the pills distributed to  
you? (PROBE WITH WHO GAVE  
THEM TO YOU AND WHERE?)

b. No



30W. Why weren't you treated for  
filaria?

(DON'T READ OUT THE  
ANSWERS)

a. Out of the village at the time of  
treatment

b. Pregnant at time of distribution

c. Sick at time of distribution

d. Health staff never came

e. Refused ⇒⇒GO TO #30X

f. Felt unnecessary

g. Fear of side-effects

h. No reason

i. Other \_\_\_\_\_

⇒⇒ALL OTHERS GO TO #30Z

30X. Why did you refuse the  
treatment?  
(PROBE)

30Y. If you did agree to take the  
treatment, what would have to  
change?

30E. Did you swallow the pills?

- a. Yes ⇒⇒ **GO TO #31**
- b. No ⇒⇒ **GO TO #30F**

30E. Why didn't you swallow the pills?

**DON'T READ THE ANSWERS**

- a. Afraid of side effects
- b. Sick
- c. Felt unnecessary
- d. No reason
- e. Pregnant at the time
- f. Forgot
- g. Other \_\_\_\_\_

⇒⇒ **GO TO #30Z**

30Z. Did you take filaria treatment last year?

- a. Yes ⇒⇒ **GO TO #31**
- b. No ⇒⇒ **GO TO #37**

31. Why did you agree to take the pills? **(PLEASE PROBE UNTIL THERE ARE**

**NO MORE ANSWERS LEFT FROM THE RESPONDENT. USE THE FOLLOWING TECHNIQUES: IS THERE ANOTHER REASON? IS THAT THE ONLY REASON? )**

**(USE BOTH PERSONAL AND ENVIRONMENTAL REASONS)**

32. Who influenced your decision? **(DO NOT READ THE ANSWERS ALOUD AND MARK ALL THAT APPLY)**

- a. Head of the village
- b. Religious leader
- c. Head of the household (male)
- d. Head of the household (female)
- e. Neighbours
- f. Friends
- g. My child / children
- h. Teacher
- i. Village midwife
- j. Health worker from the health centre
- k. Doctor
- l. No one / I wanted to take it myself
- m. Other: \_\_\_\_\_

33. After taking the medication, what did you feel like? **(DO NOT READ THE ANSWERS AND CIRCLE ALL THAT APPLY.)**

- a. Queasy
- b. Vomiting
- c. Fever ("hot")
- d. Headache or dizziness
- e. Abscess
- f. Itching
- g. Backache
- h. Pain in the groin area or arm
- i. Swelling in the groin area or arm
- j. Diarrhoea
- k. Worms came out
- l. Sleepy or drowsy
- m. Nothing at all ⇒⇒GO TO #37
- n. Other \_\_\_\_\_

34. For how long did you have these symptoms after taking the medication? **(DO NOT READ THE ANSWERS AND MARK WHICH APPLIES)**

- a. Less than one day
- b. One day
- c. More than one day
- d. More than one week
- e. Don't remember
- f. Other \_\_\_\_\_

35. When having these signs, where did you go to seek help? **(DO NOT READ THE ANSWERS AND CIRCLE ALL THAT APPLY.)**

- a. Servant of God
- b. Puskesmas
- c. Pustu
- d. Polindes
- e. CHW or volunteer drug distributor
- f. Traditional healer
- g. Friend / Neighbour / Family member
- h. Accept it as fate and did not treat⇒⇒⇒ GO TO QUESTION #37
- i. Other \_\_\_\_\_

36. What kind of help did they give? **(PROBE)**

36B. After getting help, did your symptoms go away?

- a. Yes
- b. No



37. Would you take filarial treatment again if it was offered to you next year?

a. Yes, please explain why:

b. No, why not?

38. Can you prevent filariasis/*Kaki Gajah/Boa Besar* disease?

a. Yes

b. No ⇒⇒⇒ **GO TO QUESTION #40**

c. Don't know ⇒⇒⇒ **GO TO QUESTION #40**

39. How can you prevent the disease? **(DO NOT READ THE ANSWERS AND MARK ALL THAT APPLY)**

a. Clean the mosquito breeding ground

b. Not working too much

c. Avoid mosquito bites

d. Drink medication for filaria

e. Not working in the rice fields or fields

f. Don't know

g. Other \_\_\_\_\_

40. Can you mention the ways to prevent mosquito bites? **(DO NOT READ THE ANSWERS AND MARK ALL THAT APPLY)**

a. Hang a mosquito net

b. Burn mosquito coils

c. Spraying in the area

d. Use window screens

e. Don't know

f. Other \_\_\_\_\_

41. Do you and your family sleep with bed nets?

a. Yes, every night

b. Yes, sometimes, but not every night

c. No ⇒⇒⇒ **GO TO QUESTION # 43**

42. Are the number of bed nets used, the same as the number of beds which you use?

a. Yes

b. No

**CHECK ON #42 BY LOOKING AND COUNTING THE NUMBER OF BEDS AND NETS.**

42A. **Recheck:** *Number of beds used by the family:* \_\_\_\_\_  
*Number of bed nets used:* \_\_\_\_\_

43. Do you burn mosquito coils before you sleep?
- a. Yes, every night
  - b. Yes, sometimes, but not every night
  - c. No
44. Do any members of your family sleep in the fields during planting/harvesting season?
- a. Yes
  - b. No ⇒⇒⇒ **STOP**
45. Do you or your family members take their bed net with them when they go and sleep in the field?
- a. Yes
  - b. No
  - c. Don't Know
46. Do you or your family members burn mosquito coils while sleeping in the fields?
- a. Yes
  - b. No
  - c. Don't Know

<b>THANK YOU FOR YOUR TIME.</b>
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## **A.3. TOPIC GUIDE FOR IN DEPTH INTERVIEWS (COMPLIERS)**

### **TOPIC GUIDE**

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**MAIN RESEARCH QUESTION:** WHAT ARE THE FACTORS WHICH MOTIVATE COMPLIANCE OR INFLUENCE NON-COMPLIANCE IN INDIVIDUALS EXPOSED TO MASS DRUG ADMINISTRATION FOR FILARIASIS?

### **RATIONALE**

REFER TO THE INFORMATION SHEET

### **CONFIDENTIALITY**

REFER TO THE INFORMED CONSENT SHEET

### **WARM-UP QUESTIONS**

AS YOU'VE READ THE INFORMATION SHEET, YOU WILL REMEMBER THAT WE ARE HERE TO COLLECT SOME FACTS WHICH WILL HELP THE GOVERNMENT TO MAKE YOUR HEALTH AND THE HEALTH OF PEOPLE IN YOUR VILLAGE BETTER. SO MAYBE YOU COULD TELL ME A LITTLE BIT ABOUT THE HEALTH OF PEOPLE IN YOUR VILLAGE...

(IF NO RESPONSE... THEN PROMPT WITH: ARE THERE MANY SICK PEOPLE IN YOUR VILLAGE? WHAT DO PEOPLE GET SICK FROM IN YOUR VILLAGE?)

### **LEAD IN TO INTERVIEW**

AS I MENTIONED IN THE BEGINNING OF THE INTERVIEW, WE ARE INTERESTED IN THE DISEASE FILARIA AND ITS TREATMENT. IS THAT SOMETHING THAT YOU'VE TAKEN MEDICINE FOR? AND WHAT DID YOU TAKE?

(INTERVIEWER: OH, THAT'S INTERESTING... MAYBE WE CAN TALK ABOUT THAT A BIT MORE LATER...)

### **KNOWLEDGE ABOUT LF**

ASK THEM TO TELL YOU WHAT THEY KNOW ABOUT THE DISEASE LF:

- LOCAL NAMES
- HOW DO YOU GET IT?

- TELL ME WHAT HAPPENS TO YOU WHEN YOU GET IT.
- WHERE DID YOU HEAR ABOUT FILARIA?
- WHO DO YOU THINK GETS IT MOST? (PROMPT: MEN? WOMEN? CHILDREN?)
- DO YOU KNOW ANYONE WHO HAS FILARIA? CAN YOU TELL ME ABOUT THEM?

## **PART 2: COMPLIERS**

### **RESPONDENTS' COMMENTS ON HIS OWN LF TREATMENT**

**YOU'VE ALREADY TOLD ME THAT YOU HAVE TAKEN THE DRUGS FOR FILARIA. COULD YOU TELL ME ABOUT THE DAY THAT YOU GOT THE DRUGS?**

IF NECESSARY PROMPT THE STORY WITH:

- HOW DID THEY HEAR ABOUT THE TREATMENT DAY
- WHAT WAS THE ROLE OF VILLAGE LEADER, SCHOOL TEACHERS, CHURCH OR MOSQUE LEADERS, NEIGHBOURS, HEALTH STAFF
- ANY PART YOU PLAYED IN THE DISTRIBUTION OF THE DRUGS
- HOW FAR WERE THEY FROM THE PLACE WHERE THE DRUGS WERE GIVEN OUT?
- TIMING: WHEN DID THEY TAKE THEM, HOW SOON AFTER DISTRIBUTION
- TASTE?
- SIDE EFFECTS? HOW LONG AFTERWARDS? SERIOUSNESS?
- USE THE PICTURES IF NECESSARY.

**CAN WE TALK ABOUT THE PEOPLE AROUND YOU AND HOW THEY FELT ABOUT THE TREATMENT?**

IF NECESSARY PROMPT WITH:

- FAMILY/HOUSEHOLD: ANY DISCUSSION? FEELINGS OR VIEWS ABOUT THE TREATMENT? DID THEY TAKE IT?
- NEIGHBOURS? FEELINGS OR VIEWS ABOUT THE TREATMENT? DID THE NEIGHBOURS TAKE IT?
- OTHER PARTS OF THE VILLAGE? DID THEY TAKE IT?
- ANYONE WHO DIDN'T TAKE IT? WHAT HAPPENED TO THEM?
- HOW DID RESPONDENT KNOW WHO TOOK IT AND WHO DIDN'T?

**YOU'VE MENTIONED EARLIER THAT YOU'VE TAKEN THE TREATMENT; I'D LIKE TO HEAR ABOUT THAT A BIT MORE AND WHY YOU TOOK IT.**

IF NECESSARY PROMPT WITH THE FOLLOWING (ASKING HOW THAT MADE THEM FEEL? OR WHAT DOES THAT MEAN FOR THEM?) :

- WHAT WOULD HAVE HAPPENED TO THEM IF THEY HADN'T TAKEN IT?
- DID SOMEONE TELL THEM TO? WHO? HOW IMPORTANT WAS THAT PERSON?
- WAS THERE SOMETHING THAT MADE YOU WANT TO TAKE IT?
- DID OTHER PEOPLE TAKE IT? WOULD IT HAVE MATTERED IF NO ONE ELSE HAD TAKEN IT?
- DO YOU THINK IT WILL CHANGE YOUR LIFE IN ANY WAY? FOR THE GOOD OR FOR THE BAD?

**I'D LIKE US TO TALK A BIT MORE ABOUT THE GOOD AND BAD PARTS ABOUT TAKING IT?**

- WHO DO THINK GAINS THE MOST FROM TAKING FILARIA TREATMENT?
- WHO DO YOU THINK IS HURT BY THE TREATMENT / WHO LOSES MOST?

**LET'S THINK ABOUT THE GOOD THINGS FIRST, AND FOR YOU,**

- WHAT DO THEY THINK IS GOOD ABOUT THE TREATMENT?
- HOW DID IT HELP THEM?
- WHAT DID THEY GAIN FROM TAKING THE TREATMENT?

**STILL THINKING ABOUT THE GOOD THINGS, BUT NOW FOR OTHERS,**

- WHAT IS GOOD ABOUT THE TREATMENT FOR OTHERS?

**LET'S DO THE SAME FOR THE BAD THINGS, STARTING WITH YOU,**

- WHAT DO THEY THINK IS BAD ABOUT THE TREATMENT?
- HOW DID IT HURT THEM?

**AND THEN FOR OTHERS?**

- DO THEY KNOW ANYONE WHO SUFFERED IN SOME WAY AFTER TAKING THE TREATMENT?
- HOW DID IT HURT THEM?

**RESPONDENTS TO RESPOND TO PICTURES**

**IN THIS PART, I'D LIKE US TO TALK ABOUT A COUPLE OF PICTURES THAT I HAVE HERE WITH ME AND I'D LIKE TO TALK ABOUT WHAT'S GOING ON IN THEM. CAN YOU TELL ME WHAT YOU THINK IS HAPPENING?**

IN THIS PART, WE'LL USE THE PICTURES OF THE WOMAN SEATED AT A TABLE TAKING THE PILLS AND THE WOMAN REFUSING TO TAKE THE PILLS. YOU MAY WANT TO PROMPT WITH:

- WHO'S THE MAN AT THE DOOR? THE CHILDREN?
- WHAT IS THE DIFFERENCE BETWEEN THE TWO WOMEN?
- WHAT KIND OF PERSON IS SHE? (FOR BOTH PICTURES)
- WHAT HAPPENS TO THE WOMAN WHO TOOK THE PILL?
- WHAT HAPPENS TO THE WOMAN WHO DIDN'T TAKE THE PILL?
- WHICH WOMAN WOULD THEY WANT TO BE THEIR NEIGHBOUR?  
WHY?

### RESPONDENT ORDERS STATEMENTS:

IN THIS LAST PART OF THE INTERVIEW, WE WILL BE LOOKING AT 5 STATEMENTS. LET'S READ THEM TOGETHER.

1. TAKE THE PILLS SO YOU WON'T GET FILARIA.
2. TAKE THE PILLS SO YOUR CHILDREN WON'T GET FILARIA.
3. TAKE THE PILLS SO OUR COMMUNITY WILL NOT GET FILARIA.
4. TAKE THE PILLS SO ALOR DOESN'T GET FILARIA.
5. TAKE THE PILLS SO INDONESIA DOESN'T GET FILARIA.

CAN YOU PUT THEM IN ORDER OF IMPORTANCE? WHY DID YOU ARRANGE THEM THIS WAY?

PLEASE PROBE CONTINUALLY THROUGHOUT WITH THINGS LIKE:

- WHY DID YOU SAY THAT?
- WHAT DO YOU MEAN BY THAT?
- COULD YOU TELL ME A BIT MORE?
- CAN YOU SAY WHAT YOU MEAN BY THAT?
- SO THEN WHAT HAPPENED?
- OH, THAT MAKES SENSE...
- THAT'S INTERESTING...

THANK YOU FOR YOUR TIME!

GIVE THEM TOWEL AND SOAP.

## **A.4. TOPIC GUIDE FOR IN DEPTH INTERVIEWS (NON-COMPLIERS)**

### **TOPIC GUIDE**

---

**MAIN RESEARCH QUESTION:** WHAT ARE THE FACTORS WHICH MOTIVATE COMPLIANCE OR INFLUENCE NON-COMPLIANCE IN INDIVIDUALS EXPOSED TO MASS DRUG ADMINISTRATION FOR FILARIASIS?

### **RATIONALE**

REFER TO THE INFORMATION SHEET

### **CONFIDENTIALITY**

REFER TO THE INFORMED CONSENT SHEET

### **WARM-UP QUESTIONS**

AS YOU'VE READ THE INFORMATION SHEET, YOU WILL REMEMBER THAT WE ARE HERE TO COLLECT SOME FACTS WHICH WILL HELP THE GOVERNMENT TO MAKE YOUR HEALTH AND THE HEALTH OF PEOPLE IN YOUR VILLAGE BETTER. SO MAYBE YOU COULD TELL ME A LITTLE BIT ABOUT THE HEALTH OF PEOPLE IN YOUR VILLAGE...

(IF NO RESPONSE... THEN PROMPT WITH: ARE THERE MANY SICK PEOPLE IN YOUR VILLAGE? WHAT DO PEOPLE GET SICK FROM IN YOUR VILLAGE?)

### **LEAD IN TO INTERVIEW**

AS I MENTIONED IN THE BEGINNING OF THE INTERVIEW, WE ARE INTERESTED IN THE DISEASE FILARIA AND ITS TREATMENT. IS THAT SOMETHING THAT YOU'VE TAKEN MEDICINE FOR? AND WHAT DID YOU TAKE?

(INTERVIEWER: OH, THAT'S INTERESTING... MAYBE WE CAN TALK ABOUT THAT A BIT MORE LATER...)

### **KNOWLEDGE ABOUT LF**

ASK THEM TO TELL YOU WHAT THEY KNOW ABOUT THE DISEASE LF:

- LOCAL NAMES
- HOW DO YOU GET IT?

- TELL ME WHAT HAPPENS TO YOU WHEN YOU GET IT.
- WHERE DID YOU HEAR ABOUT FILARIA?
- WHO DO YOU THINK GETS IT MOST? (PROMPT: MEN? WOMEN? CHILDREN?)
- DO YOU KNOW ANYONE WHO HAS FILARIA? CAN YOU TELL ME ABOUT THEM?

## **PART 2: NON COMPLIERS**

### **RESPONDENTS' COMMENTS ON THE LF TREATMENT**

**YOU'VE ALREADY TOLD ME THAT YOU HAVEN'T TAKEN THE DRUGS FOR FILARIA. TELL ME ABOUT THE DAY THAT THE DRUGS WERE DISTRIBUTED IN YOUR VILLAGE.**

IF NECESSARY PROMPT THE STORY WITH:

- HOW DID THEY HEAR ABOUT THE TREATMENT DAY
- WHAT WAS THE ROLE OF VILLAGE LEADER, SCHOOL TEACHERS, CHURCH OR MOSQUE LEADERS, NEIGHBOURS, HEALTH STAFF
- HOW FAR WERE THEY FROM THE PLACE WHERE THE DRUGS WERE GIVEN OUT?
- DID THEY RECEIVE THE DRUGS? IF YES, WHAT DID THEY DO WITH THEM? CAN THEY EXPLAIN WHY THEY DID THAT?
- USE PICTURES IF NECESSARY.

**CAN WE TALK ABOUT THE PEOPLE AROUND YOU AND HOW THEY FELT ABOUT THE TREATMENT?**

IF NECESSARY PROMPT WITH:

- FAMILY/HOUSEHOLD: ANY DISCUSSION? FEELINGS OR VIEWS ABOUT THE TREATMENT? DID THEY TAKE IT?
- NEIGHBOURS? FEELINGS OR VIEWS ABOUT THE TREATMENT? DID THE NEIGHBOURS TAKE IT?
- OTHER PARTS OF THE VILLAGE? DID THEY TAKE IT?
- ANY OTHERS WHO DIDN'T TAKE IT? WHAT HAPPENED TO THEM?
- HOW DID RESPONDENT KNOW WHO TOOK IT AND WHO DIDN'T?

**YOU'VE MENTIONED EARLIER THAT YOU DIDN'T TAKE THE TREATMENT; TELL ME WHY THAT WAS.**

IF NECESSARY PROMPT WITH THE FOLLOWING (ASKING HOW THAT MADE THEM FEEL? OR WHAT DOES THAT MEAN FOR THEM?):

- WAS THERE SOMETHING THAT MADE THEM NOT WANT TO TAKE IT?
- DID ANYONE TELL THEM TO OR TELL THEM NOT TO TAKE IT? WHO? HOW IMPORTANT WAS THAT PERSON?
- DID ANYTHING HAPPEN TO THEM BECAUSE THEY DIDN'T TAKE IT?
- WHO KNEW THEY DIDN'T TAKE IT?
- WHAT WOULD HAVE HAPPENED TO THEM IF THEY HAD TAKEN IT?
- WHAT WOULD HAVE TO CHANGE FOR THEM TO TAKE IT?
- DO THEY THINK THAT NOT TAKING THE TREATMENT WILL CHANGE THEIR LIVES IN ANY WAY? FOR THE GOOD OR FOR THE BAD?

**LET'S THINK ABOUT OTHER PEOPLE NOW,**

- DID OTHER PEOPLE TAKE IT? WHAT DO THEY THINK ABOUT OTHER PEOPLE TAKING IT?
- WOULD IT MATTER IF NO ONE TOOK IT? (PROMPT WITH: WHY DID THEY SAY THAT?)

**I'D LIKE US TO TALK A BIT MORE ABOUT THE GOOD AND BAD PARTS ABOUT TAKING IT?**

- WHO DO THINK GAINS THE MOST FROM TAKING FILARIA TREATMENT?
- WHO DO YOU THINK IS HURT BY THE TREATMENT / WHO LOSES MOST?

**LET'S THINK ABOUT THE BAD THINGS FIRST, AND FOR YOU,**

- WHAT DO THEY THINK IS BAD ABOUT THE TREATMENT?
- HOW WOULD IT HURT THEM IF THEY HAD TAKEN IT?

**STILL THINKING ABOUT THE BAD THINGS, BUT NOW FOR OTHER PEOPLE,**

- DO THEY KNOW ANYONE WHO SUFFERED IN SOME WAY AFTER TAKING THE TREATMENT?
- HOW DID IT HURT THEM?

**LET'S DO THE SAME FOR THE GOOD THINGS, STARTING WITH YOU,**

- DID THEY THINK THERE WAS ANYTHING GOOD ABOUT THE TREATMENT?
- WHAT MIGHT THEY HAVE GAINED FROM TAKING THE TREATMENT?

**AND THEN FOR OTHER PEOPLE?**

- WHAT MIGHT BE GOOD ABOUT THE TREATMENT FOR OTHER PEOPLE?

## RESPONDENTS TO RESPOND TO PICTURES

IN THIS PART, I'D LIKE US TO TALK ABOUT A COUPLE OF PICTURES THAT I HAVE HERE WITH ME AND I'D LIKE TO TALK ABOUT WHAT'S GOING ON IN THEM. CAN YOU TELL ME WHAT YOU THINK IS HAPPENING?

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- WHAT IS THE DIFFERENCE BETWEEN THE TWO WOMEN?
- WHAT KIND OF PERSON IS SHE? (FOR BOTH PICTURES)
- WHAT HAPPENS TO THE WOMAN WHO TOOK THE PILL?
- WHAT HAPPENS TO THE WOMAN WHO DIDN'T TAKE THE PILL?
- WHICH WOMAN WOULD THEY WANT TO BE THEIR NEIGHBOUR? WHY?

## RESPONDENT ORDERS STATEMENTS:

IN THIS LAST PART OF THE INTERVIEW, WE WILL BE LOOKING AT 5 STATEMENTS. LET'S READ THEM TOGETHER.

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2. TAKE THE PILLS SO YOUR CHILDREN WON'T GET FILARIA.
3. TAKE THE PILLS SO OUR COMMUNITY WILL NOT GET FILARIA.
4. TAKE THE PILLS SO ALOR DOESN'T GET FILARIA.
5. TAKE THE PILLS SO INDONESIA DOESN'T GET FILARIA.

CAN YOU PUT THEM IN ORDER OF IMPORTANCE? WHY DID YOU ARRANGE THEM THIS WAY?

PLEASE PROBE CONTINUALLY THROUGHOUT WITH THINGS LIKE:

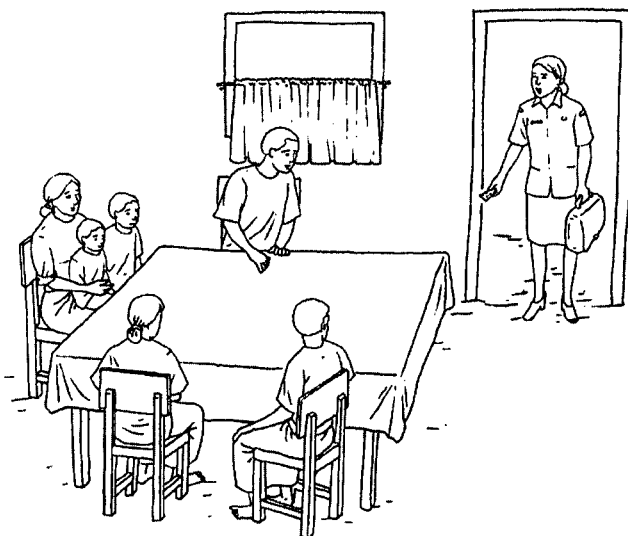
- WHY DID YOU SAY THAT?
- WHAT DO YOU MEAN BY THAT?
- COULD YOU TELL ME A BIT MORE?
- CAN YOU SAY WHAT YOU MEAN BY THAT?
- SO THEN WHAT HAPPENED?
- OH, THAT MAKES SENSE...
- THAT'S INTERESTING...



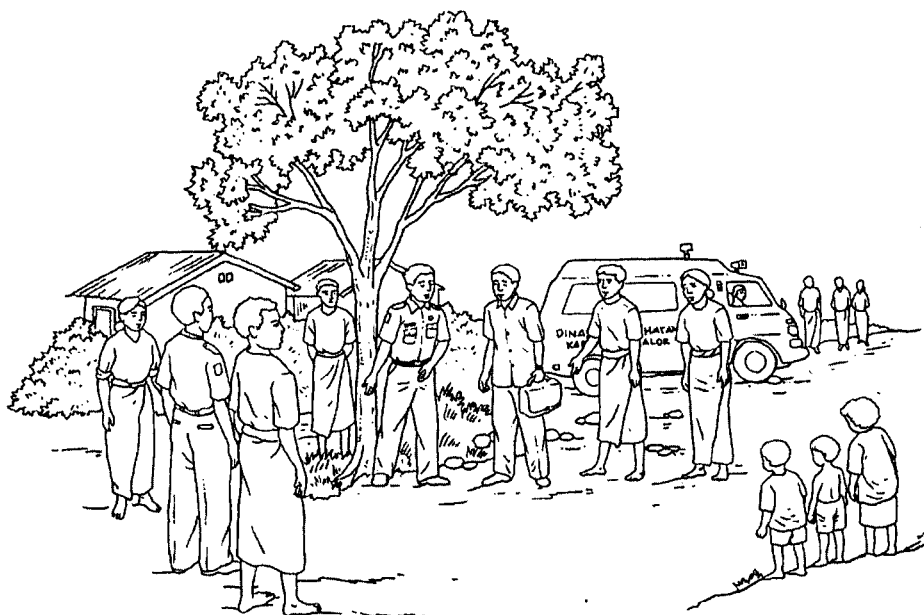
THANK YOU FOR YOUR TIME!

GIVE THEM TOWEL AND SOAP.

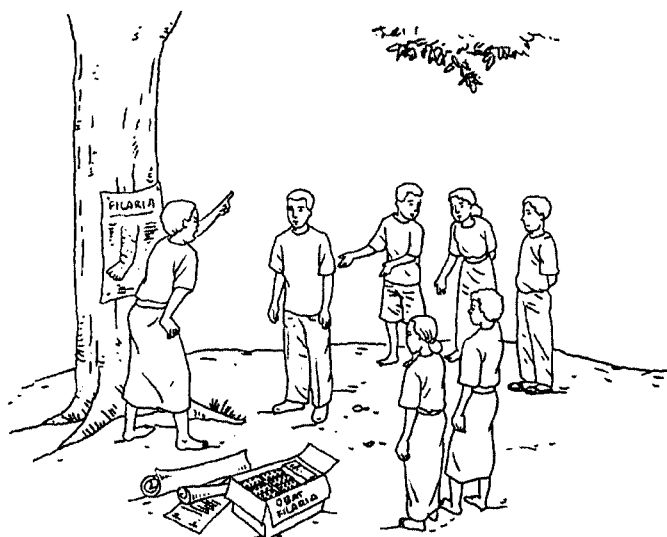
## **A.5. PICTURES DESCRIBING MDA USED IN THE IN DEPTH INTERVIEWS**



**Figure 1 Illustration of house visits for MDA**



**Figure 2 Illustration of health staff visiting villages for MDA**



**Figure 3 Illustration of angry CHW during MDA**



**Figure 4 Illustration of observed MDA**

## **A.6. PICTURES OF TWO WOMEN USED IN THE IN DEPTH INTERVIEWS**



**Figure 5 Illustration of non-compliant woman**



**Figure 6 Illustration of compliant woman**

## A.7. DESCRIPTION OF THE INDIVIDUALS IN THE INTERVIEW SAMPLE

No.	Code	Description of the individual (education, sex, age, number of children, marital status, etc.)
1	C4	female, 20's, pastor
2	C5	male, Flores, born 1957 (48 years), 4 children, civil servant, education junior high
3	C6	male, retired 1995, used to run the LF Programme for the District health authority, married, 5 children and grandchildren, education nursing school
4	NC9	Housewife, 1 child, breastfeeding, Muslim, 20's
5	C10	Fisherman, 38 years, man, Muslim, married with children
6	NC12	Female, 20's, 2 children, husband works for GTZ, Muslim
7	NC13	porter at Kalabahi seaport, married with 6 children, primary school, Muslim (born Christian, changed when he married), 100,000 Rp per month
8	C14	Male, private business, 3 children, 35 years old, Senior high school in economics, Protestant
9	C15	Woman, 6 children, 38 years old, junior high school
10	NC16	Farmer, man, 23 years, 1 child, Protestant, senior high school
11	C19	Man, 2 children, farmer, Protestant, 30 years old
12	C20	Man, farmer (part of a cooperative), 28 yrs, 1 child 4 mos old, married. Christian Protestant. Junior high finished. Originally from Tominiku.
13	C21	Man, 30 years, 4 children, Protestant
14	NC22	Man, head of household, 38 yrs, civil servant, university degree 2003, 3 children, Alorese origin, Christian Protestant
15	NC23	Woman, 41 years, 5 children
16	NC24	Woman, 24 year old, housewife, married with 3 children, primary school education
17	C25	Man, farmer, married with 7 children, junior high school not finished
18	NC26	Man, 25 years old, Worked as contracted labour for Dept of Agriculture, living w/ a woman not married yet, no children, senior technical high school - did not pass
19	NC28	Woman, 50 years-ish, married, 6 children, primary school
20	NC29	female, 17 years old, not yet married, primary school, 5 siblings, Christian, mother & father died



21	C30	male, head of household, 41 years old, farmer, junior high school, 4 children
22	NC34	Male, no personal summary given
23	C35	Woman, housewife, 28 years old, sewing school, 2 children
24	C36	Woman, 32 years old, 5 children
25	NC/C37	Man, head of household, farmer, 6 children (2 died) first wife died and remarried, 40's
26	C38	Man, head of household, 37 years old, primary school, farmer, head of his neighbourhood, 4 children
27	NC39	Woman, housewife, 47 years old, SD, 4 children (1 died)
28	C40	Man, 43 years old, farmer, elementary education, 3 children
29	C41	Woman, 28 years old, weaver, SMP, 1 adopted child, Christian
30	C42	Woman, 7 children (one died), married to a teacher, now widowed. Youngest child is now 15 yrs, oldest is 28 yrs. Born in '51 ~55 yrs.
31	NC43	Man, 2 children, school SMA stopped, 28 yrs, origin Maritaing.
32	NC48	Woman, from Rote, married 11 years, 5 yrs in Alor, 3 children, SMA (not finished), husband works privately, 30 yrs, Protestant (from research diary)
33	C49	Man, married, 4 children, university (S1) educated, 41 yrs.
34	NC50	Man, 57 yrs, has 4 children (2 died), educated SMP, was head of the school of SD Impress Maukuru, wants to retire soon.
35	NC51	Man, 57 yrs, retired teacher, 6 children, married, wife is also teacher. He and his wife are doing some extra univ courses by mail.
36	NC52	Woman, 6 children, 1 died, married, husband is a driver (he was in prison when younger) she's originally from Alor, he's from Flores, Catholic, 53 yrs, primary school educated, she is the eldest daughter and had to stop school to stay home + cook for parents when they come from fields.
37	C53	Woman, married at 16 yrs, 8-9 yrs here in Fanating, but no children. Thinks she may have been too young when married. Husband is a farmer. 25 yrs. SMP.
38	C54	Woman, Muslim, mother - Ujang Pandang, father - Alor (mother was kidnapped from Ujang Pandang), 6 children, 1 g-children, born 17/8/58, primary school
39	C55	Woman, 2 children, from Solo, Timor. Primary school educated. 53 yrs.
40	C57	Woman, Protestant, primary school educated, 7 children (6 boys, 1 girl), housewife, from Alor Timur, 51 yrs, traditional healer (massage), husband is a farmer

- Green shaded indicates compliers.

- This table represents the 40 people interviewed and recorded with the digital recorder. There were 3 people I interviewed who did not consent to be recorded. One was an elderly man (who spoke a local dialect and despite having an interpreted with me, the interview was difficult due to his particular situation), and two were women (one spoke a local dialect and communication was extremely difficult and the other was disinterested and the interview was terminated early).

- Locations of the interviews were removed.



A.8. EXAMPLE OF FRAMEWORK MATRIX (SOME INFLUENCES ON COMPLIANCE)

Code	"Serf" mentality	Reputation	Influence of important people	Sanctions, punishment + force	Gender	Group norms	Gov't	Fear	Happiness and other emotions
C4				She herself was not forced. She would influence others to take the treatment, so they would not get the disease, everyone should be aware that way.		Others also took Rx. Heard frm her neighbour about their SE. Everyone in Alor Salatan drank. In her own HH everyone took the pills!		Not afraid after taking Rx b/c believes that this disease has this medicine	
C5		He mentions that he was not persuaded to take it but that he followed the explanation about the disease and that he did not want filaria to gather in his leg... "an aduh, if my leg got big, how would I feel if I went to the office wearing a tight fitting shoe? So I drank." When asked if there was another reason, he said no other consideration, only to prevent this disease.		No one persuaded him to take it. Lines 206-8 "I already feel very happy that there was no force. I understand that this drug is good for prevention."	(302) If I am sick-don't take meds, I feel burdened, b/c have wife/children, must be healthy to get necessities of life for them. Uses massage oil or doctor. Needs to be healthy b/c means free to move about+ basic necessities. If sick/suffering in bed, cannot do anything + I'm a man. If sick, everybody's sick, if healthy, can search food for them. If sick, Ibu says to hospital or meds.	(297) ...if there is a recommendation from the health authority, we take it to prevent, but already 2 year later or 1 year later, they are still distributing it.			lines 206-8 "I already feel very happy that there was no force. I understand that this drug is good for prevention."
C6				(401) If the kids next door haven't taken the medicine yet - he would order them too. These children are our future.	(118) "I ordered my wife and children to take it"		(187) The government brings this medicine for free and they only give it so that we drink it - so better to take it now, then not take it and then when the health staff have gone home, you say... oh, something has appeared. (310-1) If we don't explain to them and we just turn up, the will say "what's this drug now" [the impression he gives is not trusting if there is no explanation]	(57-8) General community are afraid of the side effects and may not want to take the treatment.	



	(236) not having a high education being an influencing factor when discussing w/ old people.	(122-127) The interviewer asked, did the religious persons push or motivate people to comply? She answered that in the village yes, that they said it was our duty/obligation to take the drugs (there is some Islamic overtones with the word she used - diwajitkan, which refers to a Muslim pious obligation)	(261) If we force them to take it, they don't want to. So we leave it, without resentment.	(168) Her husband went to HC + took meds only for himself. He said his wife was breastfeeding + they didn't give him drugs for her. (328) woman is refusing maybe b/c she heard or she feels that her family won't get the disease filaria, so that is why she doesn't want to take it, but her husband is pressing her that she must, but she doesn't want to. (334) If her husband forces her, she may not refuse, she must want to, the problem is that the info from husband alone + that from the medical team is not going to engineer change.	(166) Everyone who was here in the village today went there to pick up this drug. (339-) If there is a neighbour that doesn't take the drugs, then we will give a good explanation in order to persuade him how he should also take the treatment because we see that this one disease is not good. So if he doesn't drink, ya we will bring the direction or the persuasion so that he will also take it do that this government programme will have results in 2010.			(171-174) I had the opportunity to say at the distribution centre that rich people, who already have a nice car and good house, but still think about our health here in the community, but if we also are not concerned with our own health, ya, then we are already really wrong.	
NC9				(189) I am thankful to ourselves for avoiding this disease, to the doctor, to those who distributed it, to everyone.	(305-) If everyone didn't want to take it, it would be an error b/c program is from Bupati (in 2010 Alor will be LF free). If we don't take it then we are already wrong w/ programme. (313) If we don't follow gov't program, it would be very wrong. Mistake is that b/c it is for our health, so why wouldn't we want it? B/c if we prevent, which is better than Rx and we have drugs then why not take them? Especially when we can't buy them. Plus program is really good + we must follow it. (341-) So if one doesn't drink, persuade him to take it, so gov't program will have results in 2010.		(201-204) Now that they know what the disease filaria is - kaki gajah and boa besar - we are now afraid, so if that's the case - better to take the treatment than soon it will come to us.	(173-178) People, w/ a big heart, are proud + thankful to receive meds to prevent disease. So that if the disaster of this disease comes, they've already taken the preventive treatment + they are proud/thankful. Are grateful for the information about LF. (182) She is proud b/c here in this village, they are poor, don't have news, so if LF comes, from they would have no money to buy the meds + we would regret that, which is why we are so thankful and proud. (189) I am thankful to ourselves for avoiding this disease, to the doctor, to those who distributed it, to everyone.	
C10									



NC12						<p>(221) We know that the drugs are strong from the health authority. They said we must pay attention when giving them out. We had another training at the Puskemas.</p>	<p>Some took pills home b/c were afraid to take pills there b/c hadn't eaten yet. Some people get dizzy. Some took a few b/c they were afraid of being dizzy. (99) Maybe afraid drugs are strong so they want to eat 1st. (166) We who distribute are afraid, b/c we show to take 3 pills, sometimes people take wrong dose. Last yr, one took 3 Albendazole/ DEC + fainted/slept + we were afraid. We are responsible b/c we gave meds. They weren't angry but were afraid b/c told them drugs were strong. Many pills for 1 family, possible for mistakes. (256) neighbours afraid of disease. (315-) fear # of pills.</p>	<p>(498) if they don't want to take it we are angry with them and follow them to their houses and we are angry and and tell them about the oterh manifestations of the disease. They usually are quiet at a response to this and then they take the pills. (seems that there is a sharp-tongued CHW in this village who does most of the yelling)</p>	
NC13		<p>(8.46) the gov't health services came to the village and the head of the village told us all to come to the village office. There was a distribution there, they gave the meds and we took it the same day or brought it home.</p>	<p>(9.25) we have to take it. (15.45) head of the village explained about the MDA and if we didn't take the meds, then we would have a swollen leg.</p>		<p>(6.20) Generally, all of the community took the meds. Already the village, community must take it, they [gov't health] already directed us to take it. ANTITHESIS OF GRNRMS (10.20) if I refuse, then I will get attacked by the disease. It is my risk alone if I don't want to take it. (12.00) Reason we have to take the meds is that it protects everyone from LF. (14.00) Maybe everyone took it. Not sure but b/c lots of community went to the village office, maybe if there were 200 people, 100 took it and 100 who didn't take it, soon they will get the disease and then they will understand that the drugs were good.</p>			<p>(5.30) we're afraid, if you don't take the LF med, then you will get a swollen leg, and then what?</p>	

C14	(124-5) this programme and instruction to comply is from the top, so everyone has to comply. From DinkKas Alor and the govt.(135-) The people feel acceptance for this, b/c LF meds are v. important, b/c maybe today or tomorrow, someone will get infected, helps that it is free. (401) Even if the people do not know where the drugs come from, they will still take it b/c this is a program from the top - from the health authority and there is no payment and we have to take it.	(310-) His wife (CHW) took b/c if not, then community panics, are afraid + will not want to take it. So we have to want to take it first to motivate them to take it before LF comes (prevnt). (319-325) if people don't see the boss do something first, then they don't like it. It is the norm in his village, if the boss doesn't do it, then they where is he taking us + start having bad thoughts. (337-342) If they don't want to take it, we wld force them. People must see. Especially in a new programme like LF.	(275-) No punishment or demand that we have to take it. More like this is free help from the health authority.				(197-) Afraid when seeing someone infected b/c it could transmit.	(262-) After taking the meds, felt fresh and happy b/c before we took the meds, it was like we wanted to be sick. now the body feels better.
C15	(93-) Maybe it is b/c of something that our ancestors did, but now we are free from that by decree (Firman). (365-6) She doesn't know what was good or bad about the MDA, it is from the health authority who already gave it out, so if we want to refuse it, we can't, we have already accepted and we have already take it. (374)The health authority is helping the people, so we cannot refuse.	(190-1) When asked if she wanted her children to take it again, she said that if the children already get it at school, and take it there, then we can't say anything, b/c they gave it at school.	(382-) If we wanted to refuse, supposing that we got sick, we would then go to the health authority and they would say - we've already given you drugs, you didn't want to take them, so now you got sick.		(268-) No real gossip about the treatment, but they heard that everyone in the sub-district was getting the pills so we didn't talk about it, they came and said to take it.	(195) the doctor from the puskesmas, they say, that he gets paid for those who take the drugs. I don't know if it is true or not. Just heard about it. If they get money, they are lucky. (318-9) we heard from the health authority that the drugs made you energised, so we thought whatever disease, me must be energised.	(167) when hearing about the side effects of the children, we were all afraid.	
NC16	(364-) if the govt works w/ others, we don't know, we are just little people', so if they care for us, we accept it. They know better. They are more advanced. They know, we don't. (373) He then says he is the littlest guy.	(14-5) government health staff, government and local leaders explain that there is a MDA which will eliminate LF. We were confused b/c we call it kaki galah.		(204-) there were others before him who took it and said that it prevents the body from being sick. (520) Everybody has to take it b/c LF can come here and if does not know people's names or it doesn't pick people, it will just come, so to anticipate, we all have to take it.	(356-) When asked about drawback of drugs, if there was something bad about the treatment, then there is no way that the govt would be able to work together w/foreign countries to treat the people...the govt of Alor also loves its people.	(13) sometimes he has seen family with swollen legs, so he felt dreadful and afraid.	(202) from the heart, it motivates me to take it so that I will not get the disease LF. (234-) Feelings of regret for failing to take treatment. (503-) Feelings of MALU /ashamed if Alor is known as a base for LF. (13) sometimes he has seen family with swollen legs, so he felt dreadful and afraid.	



C19	(372) he says they have darah kotor [dirty blood] (542) we the people do not know if other sub-districts have the disease.	(220-) the CHW goes from house to house and will say this person took it/ this person didn't.	(327-8) the religious authorities told them that those who take it, will be blessed, so they need to follow. Both Catholic and Protestant church leaders said that and they announced when the treatment would be.	(231-) may be some informal type of sanctions.	(546) all people in Alor need to take it - that would be better. So that our friends also do not get it and then it becomes filarial area. (371) people were talking (mulut ke mulut) about the blood taking and the fact that it may be sold somewhere else.	(34-) He had some friends who did not want to take it b/c they got side effects and the health staff didn't want to come and do home visits. They don't want to be taken alone to the health centre, so no worth taking the meds. (305-) health staff came late to treat SE (378) some felt that the gov't wanted to sell their blood.	(240) were angry with those who didn't want to take it - b/c we could all get the disease. But after that, we all came back to normal. (038-) people were afraid at first b/c some had swelling after taking the treatment the first time. (365) fear of having blood taken - had never been done before.	
C20			(13.50) heard from the Germans who had come to Alor that he had LF. [19.05] feels his body is good, fresh - now that the disease is gone and has been eaten by the medication given by the Germans. DEC and Albendazole. [31.45] staff from Germany who come to surmount filaria. We say this is good. (29.00 earlier in the interview he talks re how the Germans stayed w/ them one week)		[40.05] in 100 people, 75 people say take meds, then the 25 who don't - already lost b/c us frm larger grp took it. But if frm 75 people don't want to take it, then the 25 are forced to follow them. you have to follow the larger grp that drinks, whatever they do. If 75 don't want to take it, then 25 won't take it. Influence is less to take it. Influence is frm the grp who doesn't want to take it. 25 don't want to take it & 75 drink. 75 say if disease comes to you - MDA only 1x/yr. the 25 say, ok, we don't want to take it, we take risk ourselves. the larger grp influences smaller grp. [41.40] 75 want to take it, eventually influenc reaches everyone. the small grp cannot be strong alone. 75 will be stronger b/c they are healthier the next yr. [44.35] 25 will be inf by health of 75 [45.15] from before, people say I don't want to work, I don't want to follow the group or I don't want to take the drugs, but from the 75 are good, they are already healthy, the 25 will be influenced by them. If 25 don't want to work, but the 75 act as one - the 25 will be influenced.	[4.25] explains how some don't want to take it b/c they think they might die. [13.35] not afraid of SE b/c there is obat balasan. [17.25] first time, the KG people didn't get better. jangan sampai we the healthy people add more disease to ourselves with the meds.	[8.10] felt regret that he did not attend the MDA this year b/c the meds are for us. [19.05] feels his body is good, fresh - now that the disease is gone and has been eaten by the medication given by the Germans. DEC and Albendazole.	



C21	(14-5) teams from university, Swiss and German working on LF. (260) The head of the neighbourhood gives the team the names of everyone. (309) In the opinion of the head of the neighbourhood grouping (dusun), everybody took the treatment.				(379) Everyone in the area follows the MDA, including Mataru, up in the mountains. (393) There is not much standard communication between us and the other villages, it is not standard, so we don't know who took it and who didn't. In this village though, we have standard communication (e.g. we know).	(17-8) some people said that the gov't was taking their blood and then selling it as if they were blood donors. They would give it to patients in the hospital who had less blood (kurang darah). (23-) Now we understand though that they are not sealing our blood, but that this is for our health, so now we all come every year. (120-) Our government has the intention to help us people, so it is better we get treatment quickly.	(165) Very afraid of the disease b/c his father was sick and he had much grief/sorrow.	
NC22	[198/24.00] feels that kader doesn't have a high enough educ level. [221] he would believe info from someone frm a legal authority [embaga] and who gave the info thru the media all the time, then that would slowly change consciousness.	[43.45/307] I don't know if the kids took the meds b/c they were aware [of LF] or b/c they were ordered/forced by their teacher. Children have to follow their teacher.	[146] not sure if his wife took it - she is currently pregnant - and I don't know if there was info re pregnant women taking it or not. I think she probably didn't take it b/c I was suspicious for her to take meds in her condition. So maybe she didn't take it, maybe she's still stored it. [321] I wouldn't force my wife to take it, plus I see on tv re women's empowerment. I wouldn't want to be reported! [laughs] also I don't understand enough about it, plus we both didn't take it.	[173-] sometimes in conversation, comes out I didn't take it. No criticism/comment - maybe they figure it is my fundmndt right. [275/36.30] Speaking only & not do it not same effect as doing, feeling. Exmpt. doesn't knw how to drink alcohol & many in his envrmt do, he'll have to follow, even a little. I am influenced by my envrmt. If they want us to drink, should get us all together, maybe after sometime, I'll influence. we need to be together withldm & give it to all together. envrmt has a big inflnce on people's thinking. [285] env infl in city/will same - depends on educ. if already thinking logically, then no inflnce. GOOD QUOTES. if educ low, then listen to rumours. [292] maybe he'll drink too a little so as not to be alienated. [296] in the vill, they hear rumours more than weighing feelings or problems. if they had info, the could weigh feelings.	[94-] he criticises the gov't campaign for LF - not enough information. [123-] his kids were only informed that they had taken meds at school. He searched for info then he knew if was for LF. [134-] he was suspicious to see his children suffer from SE. maybe they took too many doses? B/c there was no info, we as parents don't understand. We are suspicious. [197-] critical of the kader - not a high enough level of educ, should use the gov't service - INFOKOM to distr info.	[62] was afraid that the swollen leg may be cause by the treatment or by the disease. He needed to find out information. [208-] he talks re if the LF campaign was like the polio campaign where they saw it was dangerous for their children. [if I had more info, then if my children fainted or whatever, I wouldn't be afraid. [41.45] afraid to see his children w/SE.		



NC23	<p>(242-) Govt gave pills to Pusk, then they gave it to us. We were quiet, accepted, didn't say anything when they spoke. (485-) If we know the gov't or community wants us to be healthy + the gov't helps widrgs so that we are healthy, so whatever gov't brings, we must follow whatever that is, for our own private health. But if someone doesn't want to take it, then he doesn't want his future, maybe he is happy w/ LF.</p>	<p>(204) she felt badly for her children who had SE after the treatment and she rebuked them for not asking their teacher to let them take their treatment home to take after lunch.</p>	<p>(475-) In the household, it is usually the mother who has the responsibility to give the drugs to the husband and the children after they have eaten.</p>	<p>(242-) Govt gave pills to Pusk, who gave to us. We're quiet/accepted/said nothing when they spoke. (485-) If we know gov't/community want us to be healthy, gov't helps widrgs-so whatever gov't brings, we must follow whatever it is, for our own prvt health. If someone doesn't want to take, he doesn't want his future, maybe is happy w/ LF. (494-) If there's a gov't program + we think it's to make our future better, so better to follow. If we think it's not good, has bad SE then we may not follow. Each individual makes choice.</p>	<p>(102) doesn't want to take b/c body will itch and it's like she doesn't want to work if she takes the meds. So she's afraid to take them. Plus her child itched until his whole body was red.</p>	<p>(474-) was afraid to take Rx initially - saw people w/SE for 1-2 wk, worms expelled.</p>	<p>(61-) People afraid of black magic curse of LF.</p>	<p>(210) afraid of LF.</p>
NC24								
C25	<p>(306-8) People waited for Rx after doctor told them they "had" to take it. (534-) Noone refused b/c Rx is a blessing, so we take it. God took care of it, so we take it. (532) Not drugs Indonesian made but from outside the country for us, the people of Alor.</p>	<p>(537-) This disease, we can't see it w/our eyes, but maybe the doctors see it w/a machine/tool so before we get this disease, have to take the Rx.</p>	<p>(483-) took the Rx b/c they announced that we had to take the LF Rx. He was afraid, but did it, &amp; no effect, b/c Rx could not find any disease in him.</p>	<p>(762-) If I am the head of the HH, and you don't take the Rx, it can't be. All have to take it.</p>	<p>(525-) Must take it, w/ neighbours too so that this disease stays away from us. No one here has worms. (534-) No one refused. (721-) everyone must take it. So that everyone is protected.</p>	<p>(559-) if they get LF b/c they didn't take Rx, then they go to HC where health staff say, 'maybe you have it b/c you didn't take the Rx. (538-) People will report that Alor is happy, and healthy, no disease here b/c people took Rx. (704-) People will comment if he becomes sick b/c he didn't comply.</p>	<p>(562-) there are those who maybe already know that this Rx will avoid the disease, maybe they know there will be an epidemic coming, so we should take it.</p>	
NC26		<p>(501) from the HC, say the drugs are for LF, so people take them.</p>	<p>(358) his wife complied. She told him re SE she had. Her SE made him even more afraid. (458) she wasn't forced, I didn't prohibit her from doing it.</p>	<p>(351) Almost everybody took the Rx in his village, only a few (10-11 people) didn't take it. So that</p>				
NC28								







C38	(162) if there is a need in the community, they must take care of it - "we the people here only wait" (258) His wife also didn't take it the 1st yr b/c it was not distributed to them.	(279) he just recently took it, b/c as a boss (of a dusun), he does it so that the people know it is a gov't program.	(287) he thinks people aren't forced into taking it, but do it b/c they want to get rid of disease.	(230) my wife can take it, but I still doubt it b/c the dr has not yet given an explanation. She an adult, she can take it.	(233) if from the health authority, there is no effect (on pregnant women/babies) then ok, b/c it is a program (e.g. gov't).	(179-) he explains that if there's no test, then people will doubt the meds, that they are not cook w/ the body and will cause SE. If test, then ok, they will follow the MDA. (195) someone died from SE after MDA.	(177) no need to take drugs the 2nd year of MDA as I am not sick - can work.
NC39		(202) angry and disappointed w/ those who did not comply.				(48) 3 men w/BB won't have surgery b/c someone died after BB surgery - fear of death.	
C40	(265) b/c the gov't people give it for free, we accept it, w/a happy heart. (302) "we are basic people"	(214) head of the village also took it. (220) said keep desa taking it had not influence on his own decision to take it.	(250) no one was forced to take it - people have their own willingness alone. (259) if there was some kind of force, I wouldn't want to take it, for sure.		(264) great quote. This is a gov't program, if we don't take the meds, we accept the responsibility if the disease comes.	(235) would be afraid if there was no meds, but thankfully (syukur) there are. (302) great quote. We are basic people and some will fear SE, not many, but some.	(235) would be afraid if there was no meds, but thankfully (syukur) there are.
C41					(244) kind of distrust as she goes to neighbours for confirmation of what the CHW said. (273) but then she says that the CHW is related to her + she has known her along time.	(239) afraid to comply when she saw the # of pills she had to take. (237) not really worried about getting L.F.	
C42		(23.10) she was lazy to get the noncompliers in her HH to take the meds. She was silent.			(39.50) community accept gov't programs whippiness. When help (rice, money, everything) comes people are happy.		



NC43	<p>[21.20] told people that he didn't take it. I told people jang'an sampal the drugs have another effect, like swelling. There are some for whom the meds are not cook. Like darah manis/pahit. We first have to make sure from the dr specialist or pharmacy that is ok. [22.30] he talks to other people and influences them not to take it. He tells them to wait first</p>	<p>the doctor could influence to take it.</p>	<p>[32.00] none.</p>	<p>[22.30] he talks to other people and influences them not to take it. He tells them to wait first. Let 1-2 people take it first and then we can ask them about it. If the med is real (benar-benar) if it gets rid of BB. We see at the moment, there are some w/ blood which is cook and they get healed right away. [33.30] he would think from himself about whether or not to take it. currently he is 'in the balance.'</p>	<p>MAYBE TRAD HEALTH BELIEFS [16.00] for example, we have the disease of fever (demam panas). The dr gives us Paracetamol. There is no way that we will take it. We will first ask if this drug is for headache or for fever. So have to ask first. Don't want to take it and then a headache comes.</p>	<p>[7.30] afraid to take the LF drugs b/c they are new. We are a natural society. Afraid that the drugs bring another disease, like cancer, tumour. I thought of this myself. [16.05] afraid of effect of the med, [17.30] afraid of taking the med and becoming lame.</p>	<p>[6.30] man in village w/ig BB - he is ashamed to be seen. You can see his genitals.</p>
NC48	<p>[12.40] husband not allowing her to mix with the neighbours so that she doesn't get caught up in stories, etc.</p>			<p>[12.40] husband doesn't give her freedom to go to the neighbours' house. It is enough to meet them in the public meeting places and times (like parties). Husband doesn't want her to gossip with them. Has friends, but every day, all the time, she isn't allowed, she cannot go to meet them and sit and chat with them.</p>	<p>[22.20] would feel afraid if everyone else didn't take it. I heard that everyone else took it, only me who is late taking it. If everyone takes it, and there is no effect, for sure if the drugs are not good, then some would have died. If everyone takes it and is okay, then it is only me who forgot to take it.</p>	<p>[7.15] initially didn't take it b/c afraid of 'angin'. Then simply forgot. [10.15] she was afraid b/c of the SE of her family. She gave the drugs only by among saja. So she finished by forgetting to take it. Maybe this medication was already checked by the doctor.</p>	
C49	<p>[see section in pictures as there is quite a lot about reputation there.]</p>			<p>(16.50) everybody took it. Knows b/c everybody went to Posyandu. There was a calling at the church. At the offices, they gave permission to go and get medication. Some went alone and got meds for their whole families, other went all together (same-rane).</p>	<p>(18.31) what's more, it's the gov't recommendation for us so we need to accept.</p>	<p>(9.52) afraid when seeing someone with LF maybe b/c b4 old people understood little re LF - thought it was dangerous / a curse. Only told story re how it transmits - by curse. As a child heard stories, so that makes him afraid. Afraid re contact with people. Was story told to children, not a real curse, but a story to keep to children out of the mud. (16.29) afraid of SE - but more afraid of LF. (18.25) if there was a situation where someone died, would influence my decision to take it.</p>	<p>(9.52) afraid when seeing someone with LF maybe b/c b4 old people understood little re LF - thought it was dangerous / a curse. Only told story re how it transmits - by curse. As a child heard stories, so that makes him afraid. Afraid re contact with people. Was story told to children, not a real curse, but a story to keep to children out of the mud. (16.29) afraid of SE - but more afraid of LF. (18.25) if there was a situation where someone died, would influence my decision to take it.</p>



NC50	(22.40) people wouldn't be brave enough NOT to comply b/c it is a govt decree.	(18.45) but when we tell the children they have to take it - they do. (36.00) people need to have an example when new things are introduced into the village. (37.44) he doesn't need to see watch someone. But those who don't yet understand, will need to see their friends take it first. (44.56) there was a pendeta (American) who worked in Maukuru, who told him that what he should keep taking the trad med while he is walking to the HC. and since then, he has practiced that, was the same as his parents promised. (daun papaya)	(22.40) people wouldn't be brave enough NOT to comply b/c it is a govt decree. On that day, people may not leave the village. (24.35) no sanctions for those who did not want to take meds.	(54.40) wife wasn't angry whimb b/c he didn't take it.	(55) hold the treatment, but if someone doesn't see his friend, then he won't take it. (18.45) Community in Indonesia must accept it and take it. (36.45) people if they want to live, have to listen and take it immediately. (37.15) one person can influence each other. great quote 37.29 even if it is for our health, but we see that people to the left and right of us don't understand, then we will start to bargain. (37.44) he doesn't need to see watch someone. But those who don't yet understand, will need to see their friends take it first.	(18.15) school children are running away when the midwife comes b/c their parents/adults have told them the Rx is bitter - and they are afraid! (20.34) 1st time they took it, when the drug was new, people were afraid re SE.	(49.09) feeling of fear - yes. We are afraid b/c it could shorten our lives.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.
NC51				(54.40) wife wasn't angry whimb b/c he didn't take it.	(51.14) in one area, every person has to take the meds. If there is someone who doesn't want to take it, then the disease can move. b/c it is a transmissible disease. It is better if everyone takes it.	(45.25) he thinks the drugs are not 'serious' (not to be taken seriously) (52.00) if from the govt then I have to accept it. The program for public health.	(49.09) feeling of fear - yes. We are afraid b/c it could shorten our lives.	(7.15) We believe the health authority and we are more afraid of getting sick. (10.00) [laughing] take it b/c afraid to die! (13.37) She was afraid to see people w/KG. "gilir". They are afraid. The leg was too big. They say that the disease doesn't transmit. (26.00) in the beg, when the CHW doesn't explain, people didn't want to take it.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.
NC52				(34.25) wife is involved and responsible for health in the family.				(7.15) We believe the health authority and we are more afraid of getting sick. (10.00) [laughing] take it b/c afraid to die! (13.37) She was afraid to see people w/KG. "gilir". They are afraid. The leg was too big. They say that the disease doesn't transmit. (26.00) in the beg, when the CHW doesn't explain, people didn't want to take it.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.	(7.00) we don't have KG here, but we take the pills anyway. If they give us poison we'd take it too! [laughs] GREAT QUOTE (7.15) We believe the health authority and we are more afraid of getting sick.

C53	(14.00) didn't ask any questions, just accepted the meds.				(17.15) everybody took it. (19.05) if no one else wanted to take it, she also wouldn't want to take it. (19.18) if everyone together wants to take it - then she wants to.	(14.00) didn't ask any questions, just accepted the meds.	(8.35) feeling pain, afraid when seeing the man w/KG if he moves next to us. (9.00) there are some who already were married, and then got it - there are others who got it when they were young. People aren't afraid to marry them. Family not afraid to live with them. (16.05) so many pills, afraid of what will happen if I take them all? but after taking them, nothing happened. (16.50) more afraid that the disease will spread.	(8.35) feeling pain, afraid when seeing the man w/KG if he moves next to us. (9.00) there are some who already were married, and then got it - there are others who got it when they were young. People aren't afraid to marry them. Family not afraid to live with them.
C54	(8.30) people talk and we follow, we're community (masy) so when good people come and give us good info, we have to follow.	(18.00) for her, everyone makes up their own minds - there is no force. You go - you go. You don't want to - ok too.	(18.40) her husband said you have your won fortune. It's your own risk to take the meds.	(13.55) people hear the name LF b/c of MDA and they run to get it. Lots of people - very busy (rame) at the church. (17.45) happier that my neighbours were there at the MDA too - rame2.	(16.25) great quotes (asked why she went to the church) b/c the gov't called us, so we go. We are the community, when the gov't calls, we have to follow. We are afraid - if we do not go and the disease comes, what happens? Each person takes care of themselves.	(15.15) in her family, those people who did not go to the church - they were afraid - they didn't take it. (18.15) even if her neighbours don't want to take MDA, she will go anyway, she is afraid if the disease comes. (22.00) people afraid to take meds - take empty water only. she is afraid to say anything to her friends re it. Their own personal risk.	(7.55) afraid of the disease, must take pills.	
C55		(56.4.20) believes in the midwife. Knows her for a long time.			(56.4.00) everybody took it. No one was afraid to take it.		(3.50) Afraid when we see people w/the disease. Afraid that it will transmit.	
C57	(13.00) after the distribution, she said there is no way that this disease is in the city - so no need to take it. But then better to prevent the possibility. Also there is the government. There are people who already know that there are symptoms here - so we'll take it.	(17.05) If we don't take it now, and then we look for it later, that's not good. It is better that we take it and protect against any eventuality. If everyone else has taken it and we have thrown it away? Not good. [mentions searching at RT/RW]	(18.35) better to take the drug now - b/c maybe the local gov't leaders will be angry later if we don't nd we get sick. They will say - the dr came already and you're sick now. It's your own fault! You take your own risks. They will not help you if you get sick - you go to the hospital alone.		(18.00) It is up to each individual to take it or not. If people think that they want to take it - ok. If they think that there's no LF here - I'm not taking it - ok too. Up to them. (19.15) everybody took it. All the community took it -two times.	(13.00) after the distribution, she said there is no way that this disease is in the city - so no need to take it. But then better to prevent the possibility. Also there is the government. There are people who already know that there are symptoms here - so we'll take it. (28.55) b/c the gov't has a programme we have to follow it. We're used to that. We have to follow - may not - not follow. Gives an example of FP - it is our fault not to follow.	(15.55) no need to be afraid - is won't come to us. (16.45) she is not afraid of the disease. We are all humans - God is with us.	



## A.9. EXAMPLE OF FRAMEWORK MATRIX (KNOWLEDGE OF LF)

Code	Personal experience with disease	Heard about the disease	Aetiology of disease	Human to human transmission	Affects whom the most	Nature of disease	Local name
C4	Not seen anyone w/LF	Read a book / brochure. Saw people w/ LF from Mainang here in Apui.	Hereditary, people don't take care of health, infection, or farmers work-come home tired-don't bathe b4 bed. Combo hereditary + not taking care of health.		Mostly children b/c are malnourished children so they get sick (parents' fault)	Body itches around the genital area. If swollen from the genitals, then it goes straight to the leg (or rest of body)	doesn't know because new to area
C5			He believes that the disease comes from the rice fields.	I don't know if LF transmits or not, because if it does transmit, for sure everybody has to drink the medicine. Maybe the health people know.		Leg gets big. Are always sores. If we see him walking to market, he is ashamed (malu) in front of others. Feels inferiority b/c people see he has a big leg. B4 no Rx to prevent, now not so many anymore, only old people.	
C6			(151-) He know about the worms and the m/f. He has used the microscope to test for m/f before.	He knows that it is transmitted by mosquitoes.			
NC9	(83) In this village and around here there isn't any disease. If here, it has come out in the newspaper that there are lots of cases in the mountains, in Kolana, and in the paper it said the big leg was "kaki galah" I have seen it before at the district fair in 2002 in Kalabahi. There was also a banner talking about it. When I saw them.... I can't really say.	(70) The first time she heard about it was when watching the news. I was still in Balam at that time.	(52-) A lot of diseases come from wind - we don't know today if God is maybe just fair & there is a fast wind or if dirt is in the air. We can get it if we don't take care of ourselves, take care of cleanliness, but if we already have drugs, easier to prevent. (59) Wind is from nextdoor village, from there from east, west, south. The disease can fly too, can go past communication. Some can transmit thru communication, thru a handshake of good friends. (66) Transmission thru communication can also be through saliva.		(75) Affects men most. Children also mostly affected but also adults.	(46-) Big leg, abscesses, red spots. When the leg gets bigger, then it will spread. You can't do anything for it when it is already big. They call it "kaki galah" at that point.	(36) No local name for the disease - only the local people say "not a good sickness". They say it is dangerous, so they prevent each time there is a drug distribution.



C10	(40) Here in this village there is one little patient show has already been examined and sent to be checked at the doctor's - because he has swollen genitals (buah kemaluan nya besar). He is in elementary school.	He has heard about the disease from the doctor.	He has heard that it is from worms. (46) It is a possibility that cleanliness is not good, which is often what happens in rice fields. He doesn't know how you get the disease from there.		(74) Mostly men who get it, not so many women. (Doesn't know why this is so.) Here in this village, we only have that small boy, but in the neighbouring island, there are lots and we see them frequently.	Causes kaki gajah and boa besar. Kaki gajah and boa besar. No local names for the disease.	
NC12	(58) No cases in Dulong. She has never seen someone with the disease. (341) after taking the pills, no change - just dizziness.		(42) Maybe because of worms, worms that are in the stomach. The worms are from mosquitoes, the mosquitoes bite (worms inside the blood artery) and suck up blood and then distribute the illness to other people.	(260) she goes on about how the mosquito picks up the worms from people and moves it to others.	(52) Women, men, children, adults - all can get bitten by a mosquito. 267) if you get it, you just submit to fate.	Kaki gajah and boa besar and there is also the enlarged breast.	
NC13			(6.00) we also don't know where it comes from. Maybe from mud, the symptoms come from there. Enter the swamps. In Moru, that is an area where there are swamps - Fanating the same. The leg swells from the mud.	(12.00) knows about transmission from person to person.		(5.32) swollen leg	
C14	(192) Saw cases at a church meeting in Fanating.		(148) doesn't really know. If there is a natural cause - here there isn't any. In Fanating, if you are usually walking in the mud, then that is the first influence for the disease. If we walk in that mud, we will also get it.	(177) Also doesn't know. (227) Part of the reason is b/c there is no disease in his village.	(155) those people who are in the places where swamps are - working in rice fields. (161) Doesn't know. In Fanating there are cases - towards the border with Moru. (181) More women than men. Adults, not children.	Swollen leg. (151-) itches which is what causes the swelling. There are sores. Cannot heal.	call it kaki gajah. (217) comments on the change of names- before kaki gajah now filaria.
C15	(70-) seems that there were cases in her opinion, but since they took the pills, their legs are no longer swollen.	Heard about it from the doctor and midwife and heard that they have to take the pills so that tomorrow they don't get sick	(53) From wind. Heard that there was a disease from outside of the country, so could be the wind brought it, so we have to comply. Has never experienced this wind, she just heard about it. (81) maybe hereditary disease causes it b/c there is no swampland here. (93) Maybe it is b/c of something that our ancestors did, but now we are free from that by decree. (110-1) May also be related to		(132) All adults, but here not even 5%, but in the mountains, there are many. Maybe b/c from hereditary - like in Mainang and Apui - there are many cases. Maybe more cases in the mountains b/c it is cold and there are rice fields and people work in the rice fields all the time. (wet)	Swollen leg and big breast.	



					discriminating against people w/LF (121) Seems also to be perhaps related to eating something wrong. From the everyday food and drink.					
NC16	(91-) he has never had any experience with the disease. (13) sometimes he has seen family with swollen legs, so he felt dreadful and afraid.	Saw video on TV. And say VCD when health staff went to Mataru, they brought a generator and a VCD/TV. They were embarrassed but we also laughed and thought it was funny to see the LF images. Some of the faces in the film looked like Abresse, some like Iranian people and others like Africa.	(103-6) they have malaria mosquitoes there. We say they are mosquitoes in the mud and swamps, b/c of that, if you walk into the mud directly, then you will get it. In Farating they have it, in Mainang too. The grass in these swamps is like sugar cane/tyne bamboos, the mud is yellow and if you walk on that, you get LF right away. (138-) about hydrocele, he is not really sure what causes that, but assumes it is also from stepping in the mud. In their location more likely to be swamp mud.	Doesn't know.				Swollen legs, breast, genitals, arms. (97) Starts with itching, that goes on for a long time which makes the leg get bigger. (121-126) If you walk in the mud, then you will start to itch and the longer you itch, then your leg will get bigger.	Kaki gajah or filaria. We only learned filaria after people came and distributed the drugs. We don't know where the term came from - is it everyday Indonesian or already from the people? We said kaki gajah when there are other parts of the body which swell too.	
C19	He names swollen legs as one of the main diseases in their community. (162) knows some people who have had swollen legs.	(145-) Didn't hear about it from anyone - this is a reality that we are faced with. Is a daily condition.	(49-) Fm mosq b/c this area many mosq. Prev. collected mosq. In 3 yrs, no change in # of mosq. Describes how diff mosq stand. (86-) B/c they work in rice fields, LF from fields+mosq. (72-) Caterpillars/larvae in the mud, everyday they're in the mud; don't bathe when coming home, so after a few days they get symptoms. (115-) to prevent bednet / mosq repellent (122-) not really sure about mosq - could be b/c not bathing, poor environment, health, clothes dirty) (139-) maybe sugar cane is mosq breeding place.	some understanding that others could get from someone w/disease- see lines 189+. The mosquito could bite her and then bite others.	The community - he doesn't really know who it affects most. It doesn't really affect children- it starts at 20 years or in the teens. (100-) When you can start walking in the mud, then it can infect you.	(80) swollen leg, hot fever, arm. (354-) when blood was taken, they weren't sure if the disease was in the blood.				



C20	<p>[29.00] saw in his blood the small worms swimming around. He didn't think he had the disease. The Germans did the test. Not afraid of having their blood taken.</p>	<p>[23.50] before the filaria treatment began, there was a lot of people who got filaria in Mainang b/c this area is a swampy area.</p>	<p>[24.15] get it from following someone else w/LF in the mud. [26.30] in one HH, if the father has it, then after 1-2 years, the child will get it too. People say it is b/c they sleep together [next to each other], if the mother has it and she sleeps w/her children, they will also get it. If they are in the same bed, the mosquito will export the disease to the next person.</p>	<p>[24.00] transmissible disease. If one person with the disease enters the mud and then a 2nd person enters the mud to work, then he will start to have the disease - itching until the leg gets bigger. Already big, itching, scratching, then he gets a fever. [24.53] 2-3 days later, the fever is gone. 3 mths later, fever comes again, then the leg is already big. there are sometime bintiki2. [28.00] in terms of being asymptomatic, he responds that you have to see the disease w/a tool [microscope]. Those w/o symptoms, when looking at the blood, see that you don't have disease in your blood. We can see the small worms in the blood.</p>	<p>[24.00] If one person with the disease enters the mud and then a 2nd person enters the mud to work, then he will start to have the disease - itching until the leg gets bigger. Already big, itching, scratching, then he gets a fever. [24.53] 2-3 days later, the fever is gone. 3 mths later, fever comes again, then the leg is already big. there are sometime bintiki2. [28.00] in terms of being asymptomatic, he responds that you have to see the disease w/a tool [microscope]. Those w/o symptoms, when looking at the blood, see that you don't have disease in your blood. We can see the small worms in the blood.</p>	
C21	<p>(61) Knows lots of people with LF. His own father had LF. When he had an attack he would sleep wrapped up in a grass mat, not be able to eat or drink.</p>		<p>Swamps - if we enter into the rice fields, usually here is we do not cut it once a year, it becomes a swamp and people will have already thrown garbage/feces there so the water becomes yellow and the water stops flowing. If we want to cut that swamp, when we get home we have to bathe when we get home, if not, after awhile, we will get it. Not sure how it enters into the body. (174) From mud.</p>	<p>(178) LF doesn't transmit.</p>	<p>(161) Everyone who has a big leg is the same.</p>	<p>(46-) In rainy season, if go out in rain, we get sick. If it doesn't rain, we are never free if we already have LF. (54-) Seriously sick - if you have LF, if you have a relapse, you have a high fever and cannot go far from the fire. You can't eat or drink until the heat goes away. (155-) It itches first, then we scratch it, it itches even more, but if we scratch it really hard, it hurts + if it is like that, then it swells + we already have it.</p>
NC22	<p>[58] saw it in Mainang - swollen legs. People said it was filaria.</p>	<p>[line 31-] he has heard re the Rx, but doesn't know re the disease. [32] A foreign disease to him. [53] transmitted by a mosq. Doesn't know if it is a bacteria or a virus. He hopes it isn't a virus b/c that would mean it is easily transmissible &amp; unable to cure, need a vaccine. Here they are taking a pill.</p>			<p>[109] doesn't know. He has only seen the one guy who often comes here.</p>	<p>[58-] saw it in Mainang - swollen leg</p>



NC23	(43-) heard people from Mebung talking about the disease and heard that it was dangerous.	(71) From before, from Mainang behind the mountain. Were some people there with swollen legs. (157-) enters the body - when the seeds of the disease are in the ground of the swamp, and when we go and walk in that mud, enter into the body through the gap in the nails, or thru blisters or sores on the leg or the pores. Then itches. (183-) the swamps have to be wet, disease likes damp areas.	(79-) Yes, she has heard that it can transmit from the water that they walk in [in Mainang]. If we go and walk in the swamps where they walk, then we will quickly get it. She has never been there so she not sure if this is true or not.	(44) Won't affect old people, but affects young people. (88-) More disease in mtns b/c swampy area, far from sea, less salt in their bodies (eating, drinking, bathing). B/c disease [lawar] goes away in body w/ salty water, people at beaches won't get LF. Only in mtn areas. Wind change constant at beach, b/c it comes from the sea. Maybe LF likes cold areas better. (124-) Sweet/bitter blood. (147-) affects anyone - adult or children/man or woman/dirty or clean, if it agrees w/our blood, then it is easy to get.	None.
NC24	(330-) her child got a traditional/culture bound illness "helasiik" after taking the filaria drug. There is no med for this disease, only trad massage. Symptoms incl: black eyes, difficulty breathing, veins in the neck?, hands/legs tight. Need to go to the trad healer for a cure. Other children had the same effect after taking meds.	has heard about it from health staff/	(49) walk in swamps, where kangkung grows, or from water tank, leg itches, then swells. Rel between mud and water. (58) Worms and influence from mosq from water, if he bites, itches. Enters the stomach thru the leg. Mentions malaria.		
C25	(162-) has had LF e.g. itching leg, itches until bleeds and then he puts salt on it.	heard of LF while in Fanating. Saw pictures at health centre.	(151-) Disease from Mainang. Maybe b/c air, water. If you walk in water that has been in the sun in Fanating, then the leg starts itching, until swollen.	(172) Mud/water cause - like in swamps or kangkung fields- maybe a mosq brdg area. Maybe tropica mosq - which hurts when it bites. Mosq nr the church in Fanating.	Swollen legs. Itching. (187-) LF enter b/c blood is not 'cokok', so must enter.
NC26	One of the diseases people are most afraid of (wimeasles)		(34) Mud in rice fields. Mud is black w/grass. Walk in it, bacteria enters body thru pores - stays. Others say it comes fr magic. People give it so you lose your way, b/c of jealousy. (71) you can know if fr mud or magic - magic comes=swells - mud, people working in rice fields doesn't know (64) not mud, has been working there for years and legs are normal. Health people say fr. mosq. (89) disease just comes. Maybe from environment. Don't understand.	(116) if working nxt to someone in the rice fields who has LF, he is afraid of transmission. (124) No human to human transmission.	(26-) symptoms start after walking in swamp mud a long time, then itches, they scratch, legs swell. (95) LF the same symptoms whether cause from magic or mud, except, fr mud, there are sores, fr magic, just swelling.
NC28	Heard about treatment, about LF, which is in her village.			(100) before was more disease, now less. Not sure why there is less now, (116) used to be older people. Same men and women.	use filaria (mentions HC use this name) and kaki gajah.
					Fotok-foka, Fotok-kaki, Foka-besar (someone else gave the answer)



NC29	her grandmother had KG. her neighbours have it too.		(67) working in rice fields b/c lots of mud, walk in there, legs start itching, then swell. Mud is red. (74) also comes from ancestors who have KG (136) Dutch brought it (185) ancestors who work in the mud.		everyone - father, aunt, grandparent, all. (161) only in Fanating area- nowhere else in Alor.	leg itches, turns red and swells. No way to prevent it.	Foioiki-fokai, fokai-besar (Abui language)
NC30		yes, from health staff.	(92-103) fr mosq, living in swamps, makes seeds there, comes out 11-12 pm, bites many pax.(111) LF in the blood, then sm worms (has seen w/researchers' microscop).	(7) easy to transmit (35) mosq	(13-4) W/current generation are fewer cases than before. Incr prev activities + LF Rx. (26) Disease doesn't know age. Pax w/low nutr get it quickest.	(8-)fever, itchy leg, scratch + sores form, swells. Hard to treat at this pt.	
NC34	both BB and KG in Mantaling.	yes frn NGO then frn DHA, used a film. (72) heard about BB.	(66) scratching, itching then KG. Some heal + some stays KG until they're old. BB frn wrking hard/wrking, some can be heard by massage-some not (73) BB rmy prob. mny wrk, wlk			(50) know re KG, but unclear. Maybe re to malaria?	(91) BB = balang, KG = gelang balang, gelang-kaki, balang besar. (Bahasa Kilana)
C35	(72) her own husband has been massaged for BB.	(63) yes BB. (70) disease frn a long time ago - old people talk about it.	(65-) working hard, walking a lot.(109) comes out after having coffee/tuak.	(124) no. is frn hard work.	(66) men, boys, young men. (103) not really sure how women are affected.	(85) fever, swelling in the groin. Body not comfortable. Scratching. (110) stomach swells, intestines ('shiny stomach') frn the liver come out. Then the testicles become big.	
C36	(80) she has seen people w/the disease - then lists villages	yes.	(72) don't take care of health.		(76) everyone -men and women	(53) BB for men, kidney and large leg. Fever comes as well. (KG) swollen leg	
NC37	(33) lots in his area. (57) before more BB, but now not so much b/c people have learned to prevent it - keeping clean, eating well, wearing clothes.	(24) yes frn nat'l team- KG. (98) knows KG and BB are the same disease.	(41) don't know. In the opinion of the health staff, frn filaria mosq, (48-53) great quote - has knowledge but doesn't believe it!	(206) yes (397) describes again	(109) won't answer (403) is relevant to every individual	(31) leg and arm swells, then gets bigger. (82) shivering, fever, hotness, then they have swelling - sometimes it goes away, sometimes not.	
C38	(61) 2 people w/KG in his village & some w/BB. They went for an operation in 2002/3. (118) saw frn Maukuru as well.	yes.	(50) opinion of the dr, it is a mosquito. He is not sure if there is another way.	(380) yes	(101) women.	(8) with KG can't walk anymore. BB blocks normal living. (41) accidg to dr, shivering evry day (70) makes walking difficult: walking far, leg's heavy, risk of infection, water comes out, BB like that too. Can't leave village.	
NC39	(27) 2 men in village w/BB- went to hospital (by car), came home + died. Stitches came undone when he worked. Other man ok after surgery.	(42) yes, in the village (kampong). (48) 3 men w/BB in village (gives names) but they didn't seek Rct b/c afraid to die. (66) 3 women w/ KG	(46) eat/drink+work. Pick something up when young, climbing or working (KG + BB) (76) eating yesterday's food (82) old people say hereditary (95) frn water in the forest		(63) men - BB / women - KG (103) not children.		



C40	(59) have BB in their village, but doesn't know about it.	(39) yes. (72) heard of KG (52) yes, BB	(67) doesn't know, but accidg to the dr. frm most. (72) other cause incl sitting down wia dizzy head, if someone sits a long time withis, then arms/legs become acid.					
C41	(9) she knows re BB- says that everyone in Mosman has it - everybody! Heard re the surgeries in Kalabahi.	(50) lady who lives not door has KG, and another in the hills. (76) maybe BB and KG are different.	(28) lots of water and mosquitoes. 4 swamps in Mosmen. (38) doesn't know where KG/BB come frm. (56) explains how it comes frm washing w/salty water. Also cooking w/salty water.	yes	(89) unclear in her answer - but seems both men and women.			
C42	(9.55) one person (orang tua) in their family who has BB. [11.45] was a woman too, but she went to Kupang. [12.30] no way to get better - for the legs to return to normal.	(5.10) never heard of filaria. KG has heard of BB - people in their area have it. (6.04) in one area, some people there with BB. (6.32) in Mausemang, a guy got it from 'air muda' and the disease wouldn't go away. He wore a skirt, so we don't know how it is. He went to Kalabahi for an operation and now he wears pants. It's a member of her family.	(5.30) doesn't know. No one else talks re it - don't know frm those who have it how you get it. (8.00) maybe frm mosqu & Mausemang, water is yellow. People have BB there b/c of water. There is lots of malaria too. Mosq here bite the same. people can see w/glasses what makes the water yellow. If people travel thirsty (bilang malas tau), they will directly drink frm river, too many sarang nyamuk in Mausemang. (9.20) lots of water collected around. (6.32) man who got it from air muda.		(10.39) KG - if they go to the HC, they will feel better. If not, they will swell and coral-like formation comes.			
NC43	[3.15] men have BB here. I have had it too 2x. From swimming in the sea, to get fish, come home tired and directly get it. [6.20] there has been someone here who has a big BB - he is ashamed.	[6.45] for the man w/ig BB, the doctor/NGO brought drugs but it had no effect on him.  [3.40] has heard of KG, but doesn't know what it is. It has meds. [4.05] then says she hasn't heard of KG, or its symptoms, or BB, or filaria. <u>Also never heard that there was medication.</u> [4.55] then says she has heard of it from the kader, but doesn't know anything.	[1.47] can come frm eating /drinking & frm cleanliness & frm animals. Can infect other people. Infects thru cooking, like leaves w/snake (worm) bites (?), like rice w/lots of dirt in it, when mixed while cooking, then upsets the body. [4.45] get BB frm swimming, working, climbing trees. [10.00] comes frm the fact that everyone is working hard, not restig enough, swimming after work hard. Also is a hereditary disease: can't get rid of it, except thru an operation & then another disease will come. B/c is a hereditary disease, if you have it since childhd, then it will continue, you can't get rid of it.	[24.45] can move from person to person. B/c it is a hereditary disease. For ex, there are 5 people in a family, older sibling has it, he has a child, then he will right away get it. It transmits. Not everyone in the family will get it. BB - that is frm lots of walking, not enough rest.	[3.15] men have BB here. I have had it too 2x. From swimming in the sea, to get fish, come home tired and directly get it. Maybe the musclevain is not in the right place anymore, [he may be talking re hernia]. The musclevain is not in the right position after swimming. Can also be from climbing trees.	[19.20] call BB Walla Balang.		
NC48								



C49	(8.35) has seen it. When I go to the village, yes.	(4.40) yes. Before lots in Farating, Bukapting, Mainang. (5.10) not as much disease as before. (5.37) people understand better now - people use soap. Not so much germs. More health centres + better transport.	(4.49) lots of LF b/c people go into the mud, b/c lots of swamps, so that the leg starts to itch. (6.26) story from before - there is a kind of worm in the mud that sucks blood and then enters the body thru the skin. (7) Swamp areas. Also mosq are there. Animals (wild pigs too) enter into the mud too. Mud w/water. No sp colour.	(7.48) No, except there is another contact with mud, then can get it. Hereditary cannot. (12.38) not afraid of contact w/people w/LF - b/c transmits via mud.	(8.15) more men who have it, maybe women have it, but I haven't seen it that much.		
NC50	(0.09) lots of cases in his area. 1992 MDA came from America. Came straight to Bukapting - most troubled area. (10.15) people in Maukuru - in KG and BB (14.30) 2 men in one family.	(7.21) BB has heard about it. (8.27) not sure if BB=KG. Can't ask b/c in the village you can't just come out and ask, they might get angry w/you. (8.58) BB- become cured by regulating the theft w/ the person who forbid it. Eat sni + spit.	(3.31) LF infectious - from mosq (7.35) BB- if there is someone who is forbidden to enter someone else's land/crops, if they enter their land, they will get BB. Some say this isn't the case anymore, but not sure. (13.14) others say that BB=KG is hereditary, cannot get away from it if you have a family member who had it. Lots have gotten it that way.	(3.31) yes. Transmits when sleeping nct to someone w/LF - he needs to have someone help him. (4.08) once the one whose sick gets better, the healthy one gets sick. (5.55) transmits by mosquito - blood moves from one to another. (6.45) moves from sick person to well person. Doesn't understand the science behind it.	(11.10) those who aren't careful - for sure will get it. Those who aren't careful about washing, keeping clean, etc. House should also be clean. Rain water will bring mosq. (14.08) men. Children - no.	Shaking (4.05) someone who is sick cannot sleep alone, needs to have someone w/ him. (21.50) Fever, shaking.	
NC51	(24.10) has heard of some research done in Apuri re mosq by the Germans.	yes KG + BB (27.20) in Alor there are 14 kinds of filaria. Heard about it from the researcher. (28.29) in lembur and Bukapting, mosq from Australia. (34.48) young boy who was taken to the boat (US) after the earthquake to be operated on.	(29.04) mosq into the mtins. (31.15) from the mud. (32.06) disease comes into the body thru the pores of the skin. (35.28) could be hereditary - as people have lived in mosq areas for a long time.	yes.			
NC52	(19.54) KG cannot transmit - what she heard from the person who had KG, he said it was b/c he worked in the rice fields.	(5.37) ya, KG. (6.55) don't have KG here. (10.15) when we were little, in the direction of Moru had it - but now, no more cases. Now people are clean (in their legs) so there is no more disease. (11.42) BB -	(10.30) from working in the rice fields. Were worms there. (11.00) says that it comes into the body from mosq. (14.00) before in the fields, people had to stomp in the mud to create (3.45) walk in the mud every day. Not sure though. Usually people who work in the rice fields who get it. Maybe from mosq bites. (5.45) there was a man who has it - who told her that he cannot share soap w/ his family members b/c he will transmit to them the disease. Interesting story. (8.00) anyone can get it if they work in the rice fields - if you don't work in the rice field impossible to get it except for soap?	(19.54) KG cannot transmit - what she heard from the person who had KG, he said it was b/c he worked in the rice fields. We don't	(6.55) swollen leg		
C53	have some living in her village. (5.45) story told to her by the man buying soap. (8.25) knows the man w/KG, but has never talked to him.	(2.54) Kg has heard of it. In Farating, there are a few people w/KG. In her part of town, there are. They are working in the mud in that part of the town. We work in the ladan (dry fields). (5.14) people from Mainang(?) all have it. (9.40) BB- no.		(5.00) yes. (5.45) soap can transmit it from person to person. Only soap - there is no other way. Shower is not enough.	(7.25) children, adults, young can b/c in rice fields.		

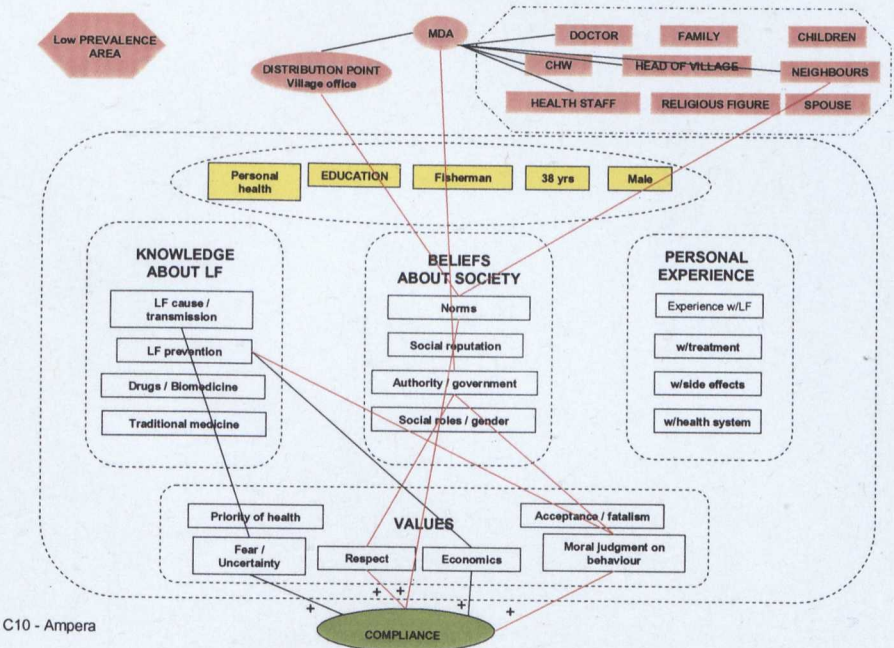
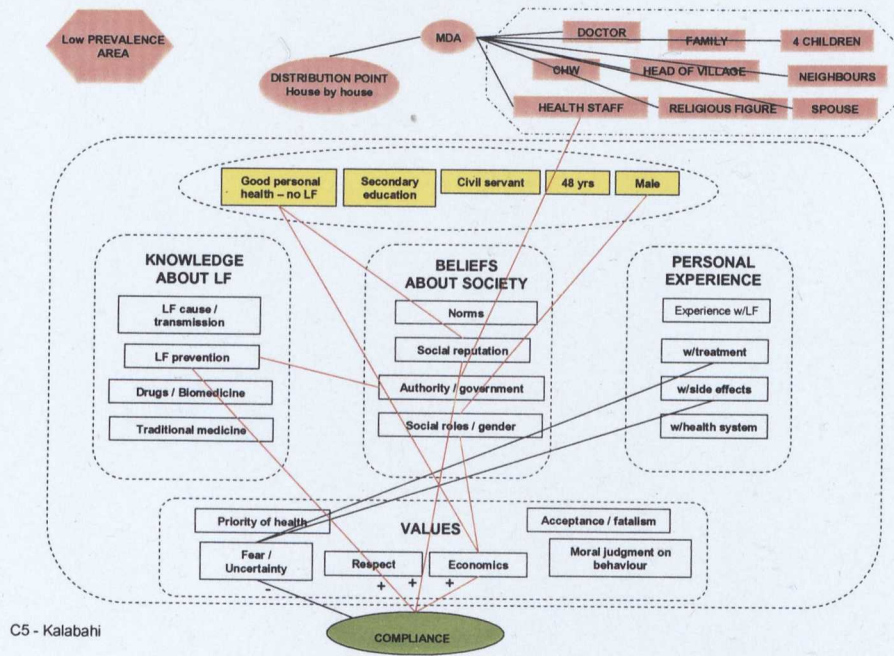


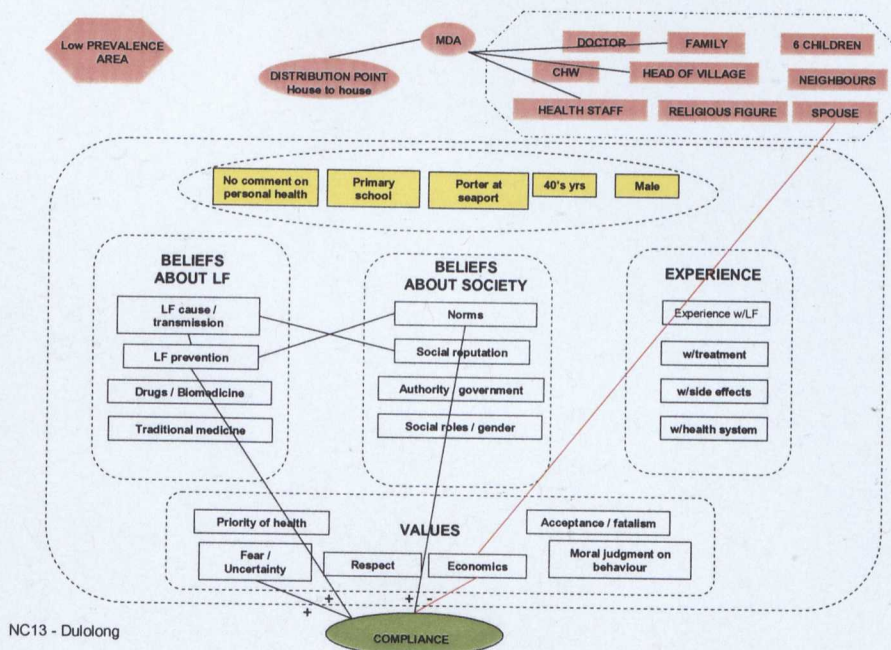
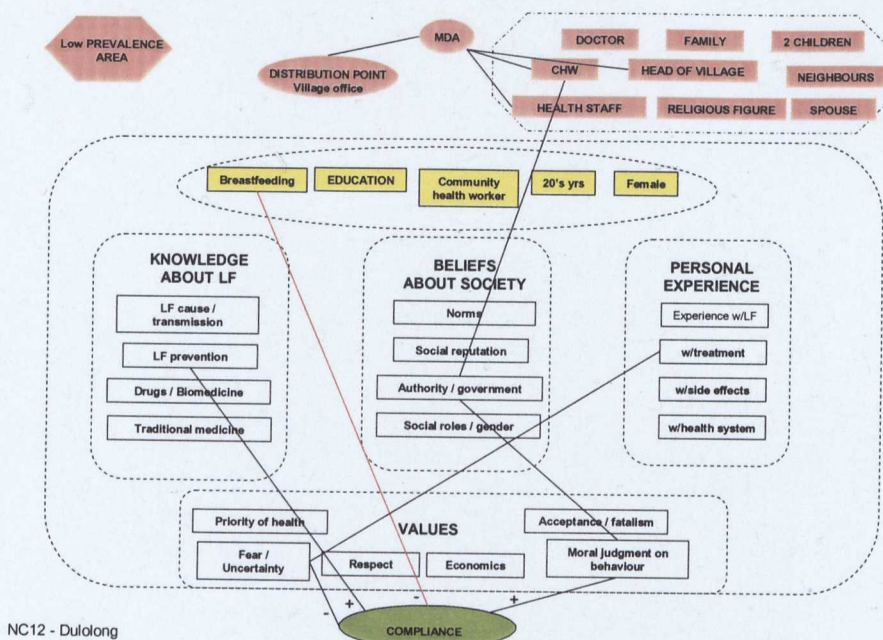
C54	(9.15) lots of people w/KG in Pailaeng.	(6.45) yes. Has heard of BB and KG - at the church there was a prog + filming.	(6.05) maybe eating a problem or going to the rice fields/swamps, which is not cook-cook w/us, get sick. Little bacteria frm pax.	(9.50) yes trans disease. KG trans. Afraid if we go and mingle withem we might get it. Has to be wetness and swamps also nearby.	(8.45) people here - many from Pailaeng - the people who work in the rice fields.	(10.45) itches when you get disease. Other than that, she doesn't know.	
C55	(3.15) has seen people w/KG - in Fanating.	(1.25) heard about it on TV. BB.	(2.17) eating sugar - sweet things. KG - caused by walking in mud - in the rice fields. (4.55) not sure how it enters the body.		(4.25) in Fanating, both men and women have KG. children no. Must walk in the rice fields to get it.		
C57	(9.15) she explains how she has helped/massaged people before for BB [which I think is hernia] . (15.40) she has seen people with KG.	(5.45) yes. It was on the TV some weeks continuous. Called KG. (8.45) BB has heard about it before. Has to do w/working hard.	(6.00) when you walk in mud, comes out directly swollen. (6.50) in rice fields like in Fanating. Bukapting. They work in rice fields. The mud is not cook2 + they get LF. Maybe already have LF inside body + then walk in mud + LF comes out. linked w/cleanliness. in the village - more impliant to work than to be clean. (9.05) BB linked w/working hard + nerves if not cocok, then comes out. she has massaged people before.	(6.00) knows it is transmissible.	(11.15) in the city, we don't have it yet. In the villages, Bukapting, Moru - they have it. It is just like that - more LF in the village. Because in the village they are more concerned about working not cleaning the house.	(6.00) swollen legs	kaki gajah.

\*The whole framework matrix is too large and cumbersome to reproduce here. However, if you would be interested in seeing the full dataset, the excel file can be provided upon request from [amkrentel@yahoo.co.uk](mailto:amkrentel@yahoo.co.uk)

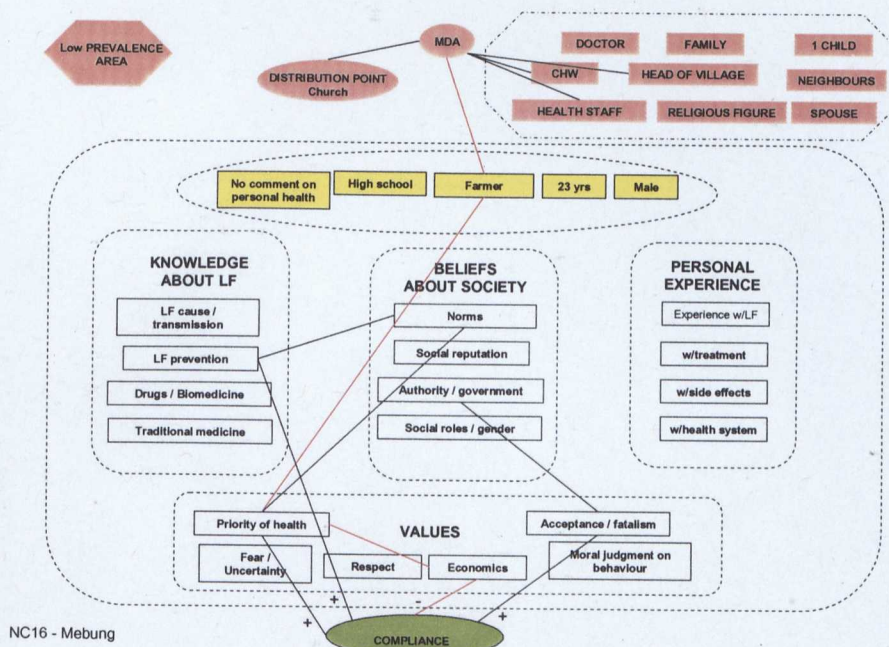
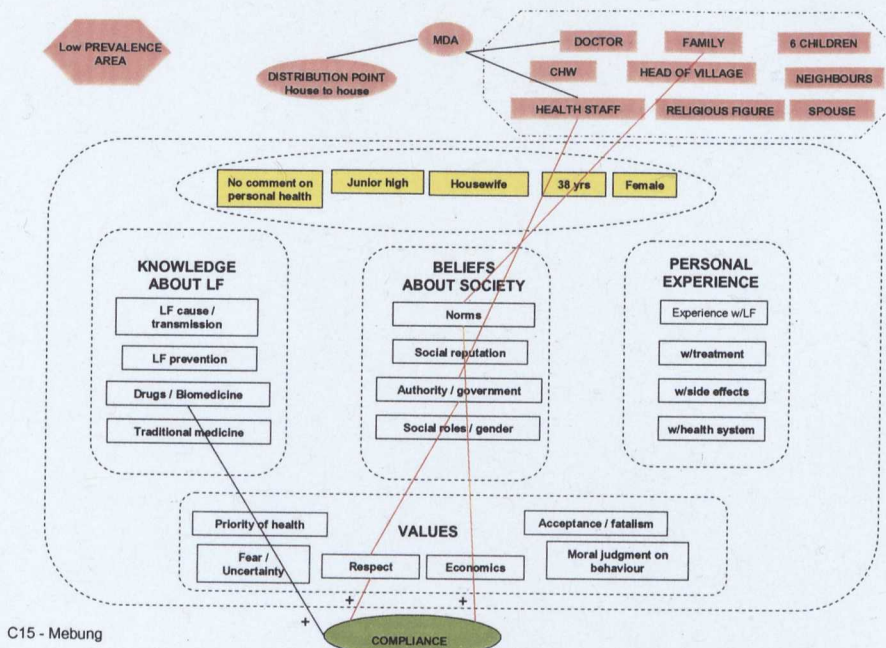


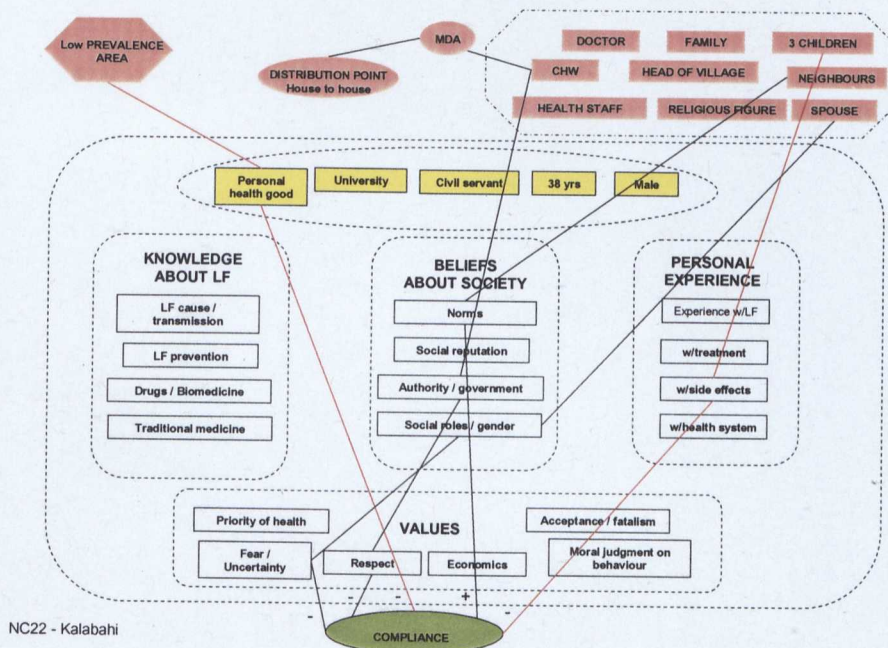
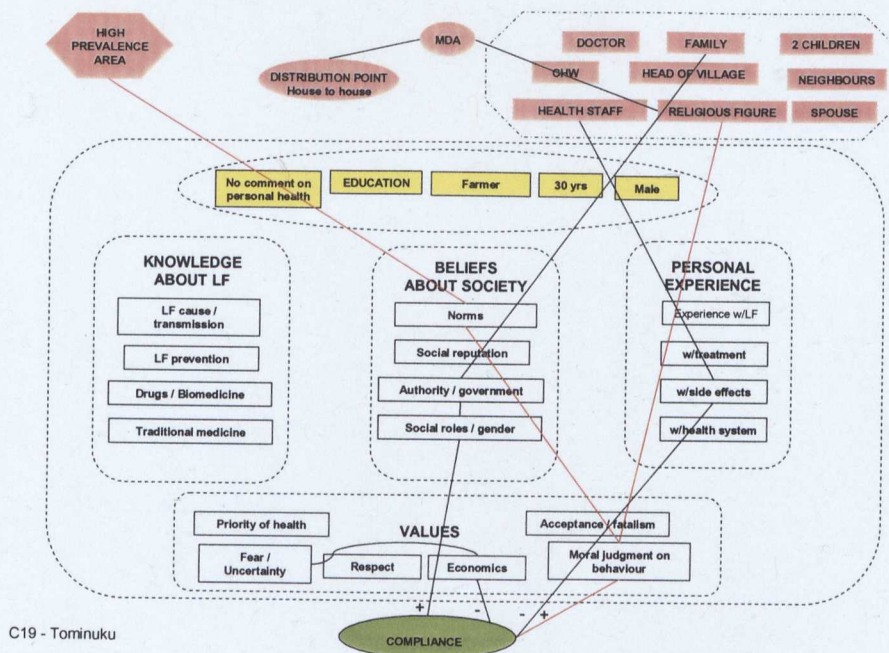
# A.10. CAUSAL CHAIN MAPS FOR COMPLIANCE



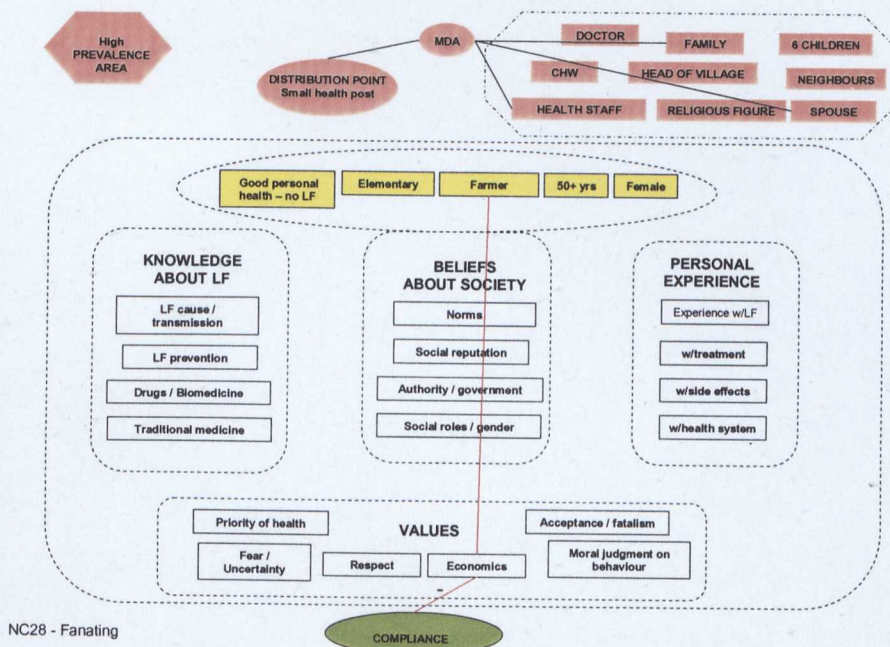
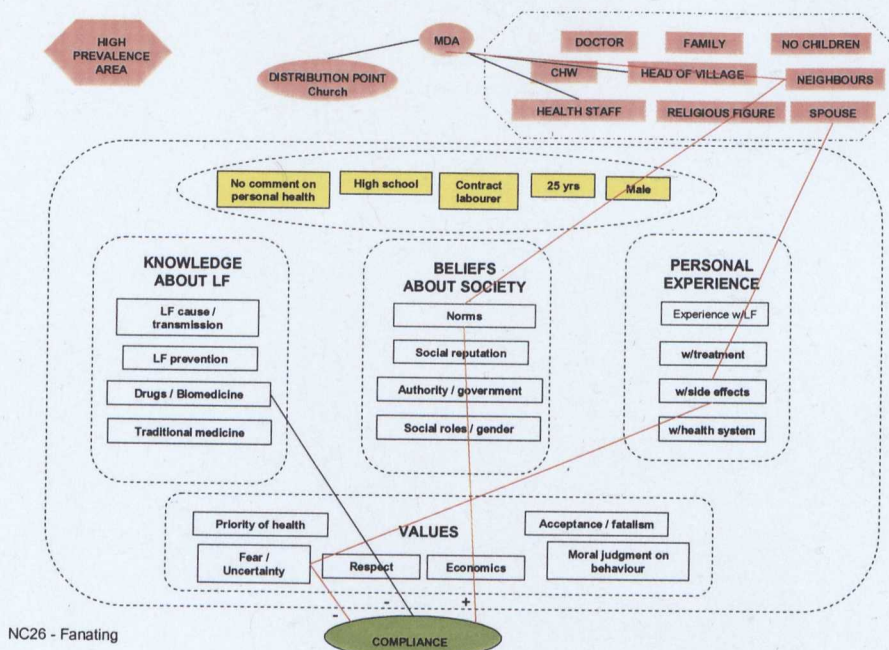




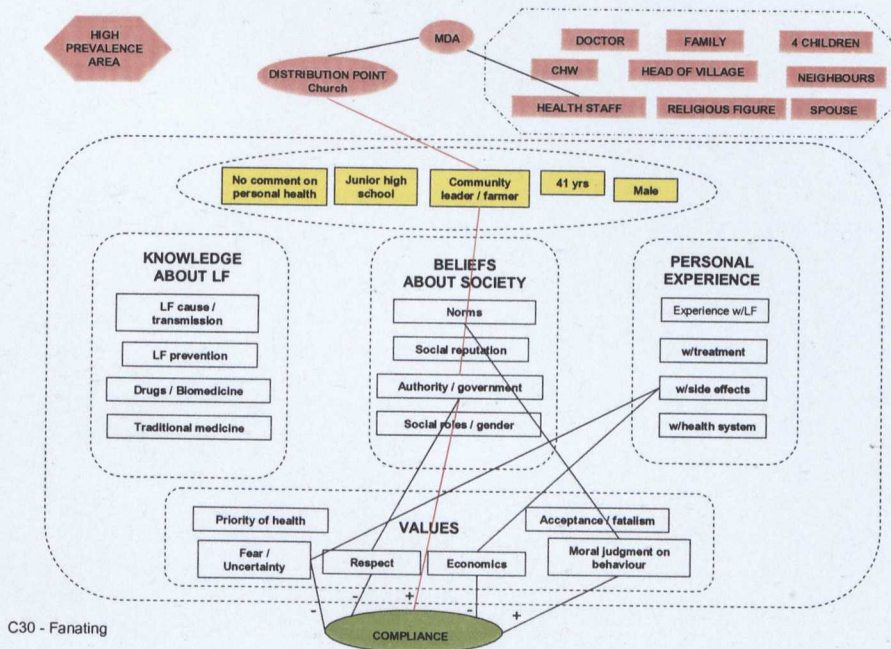
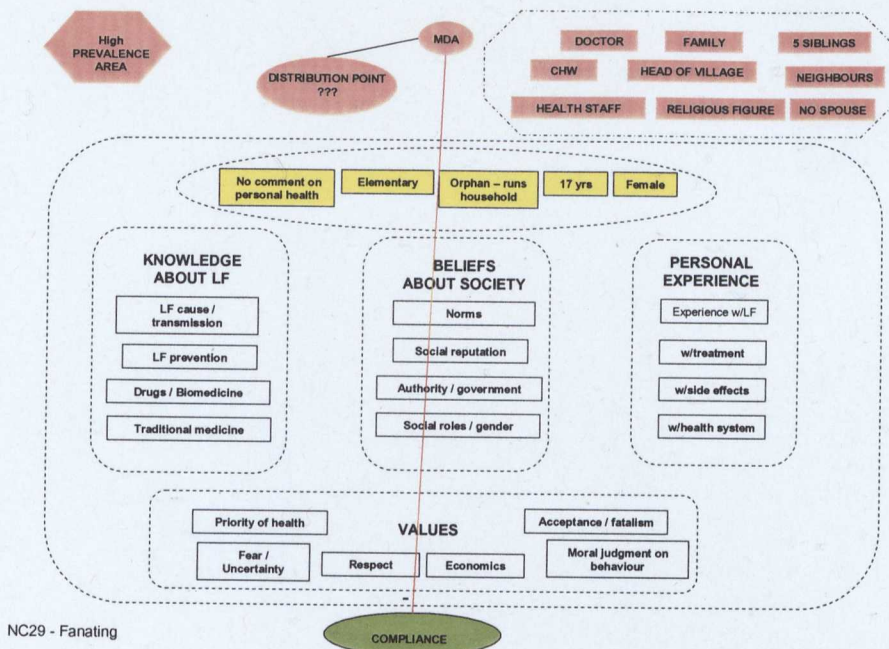


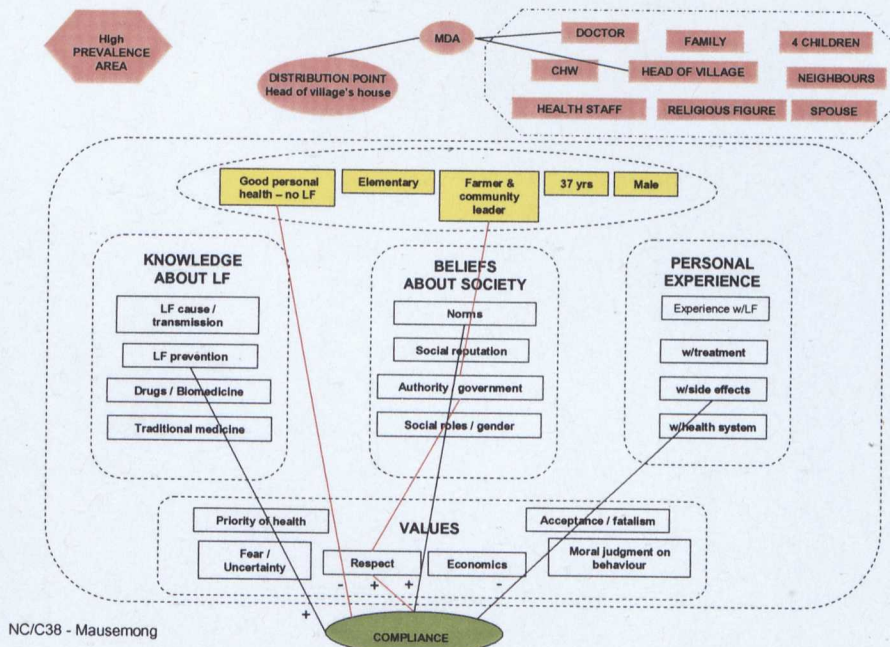
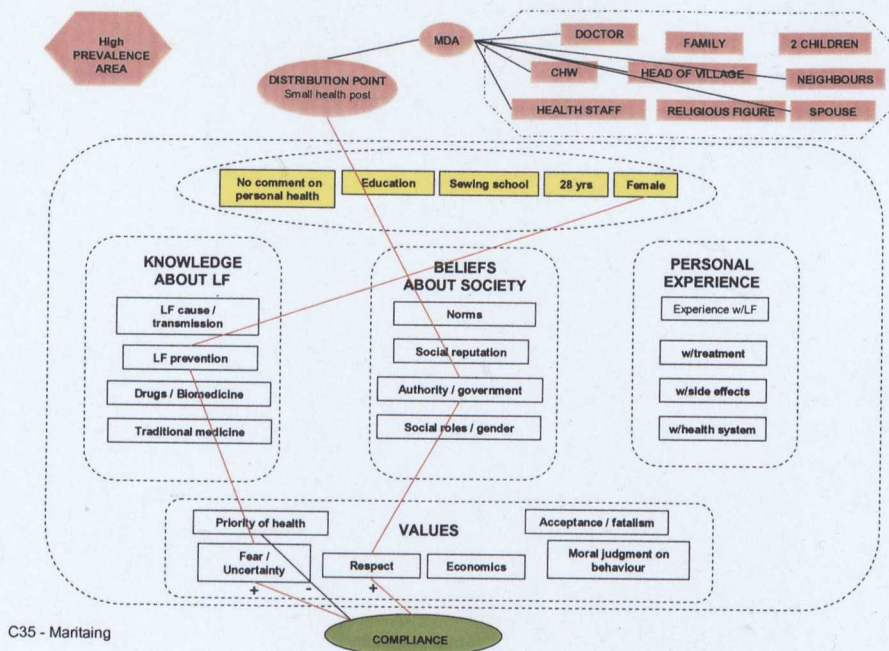




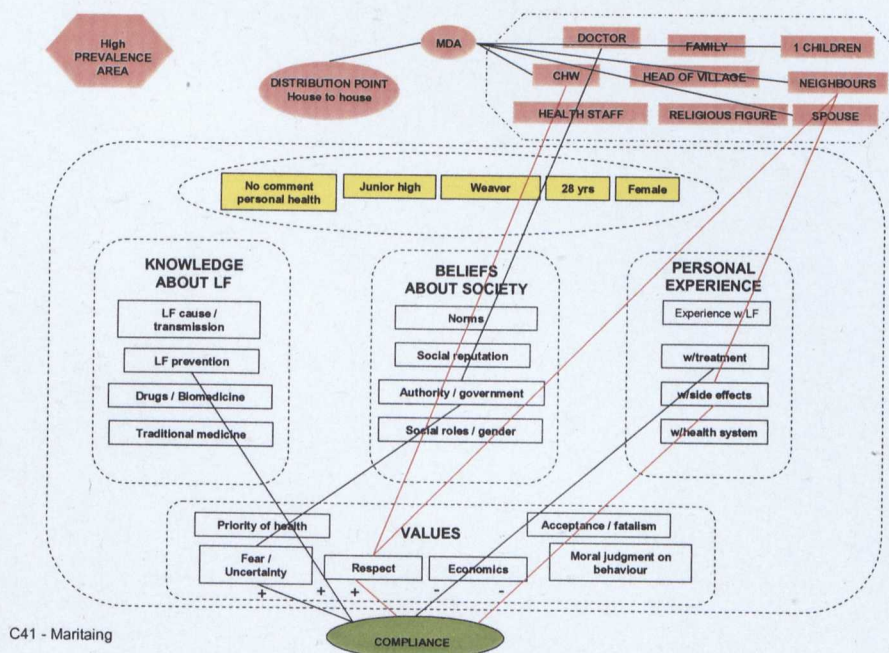
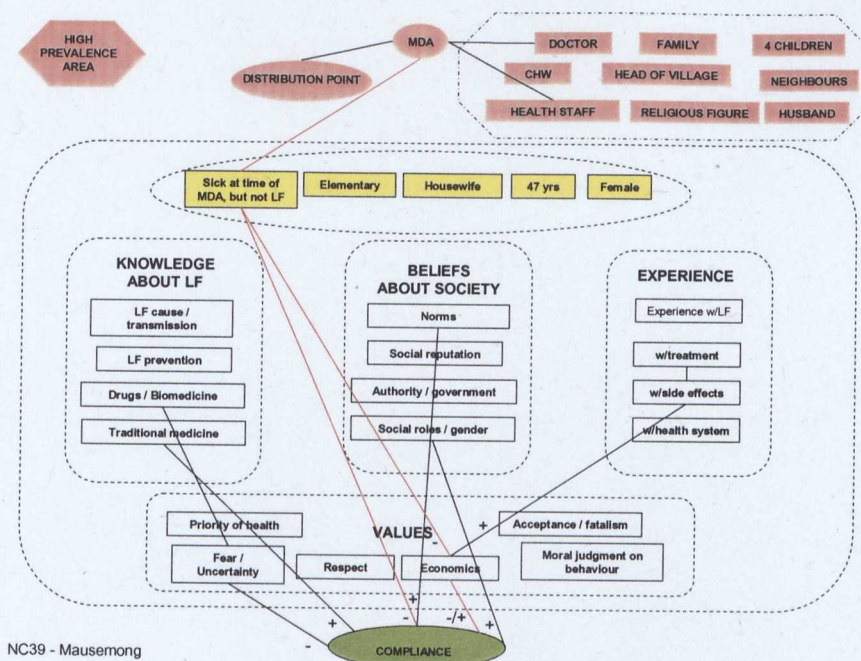


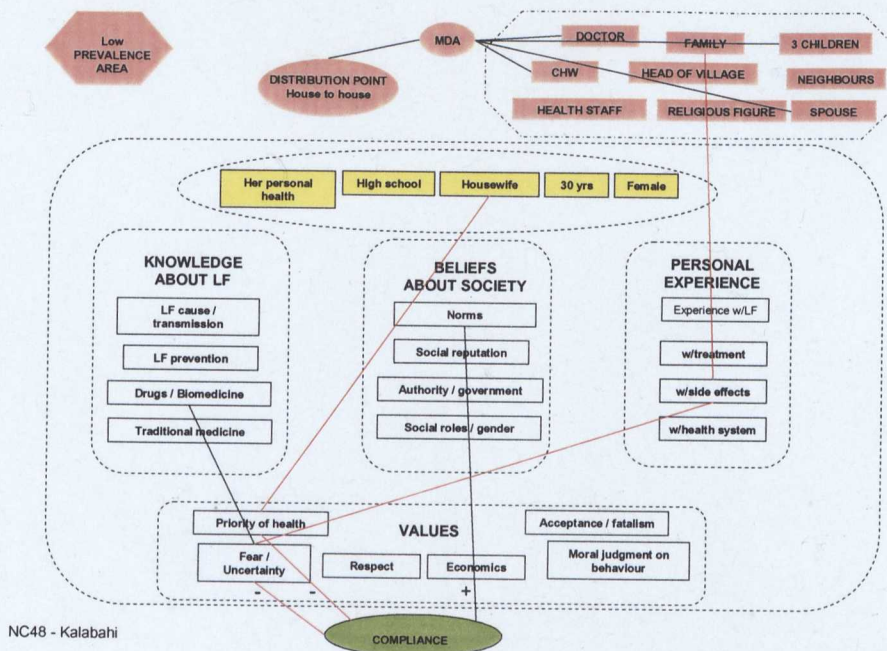




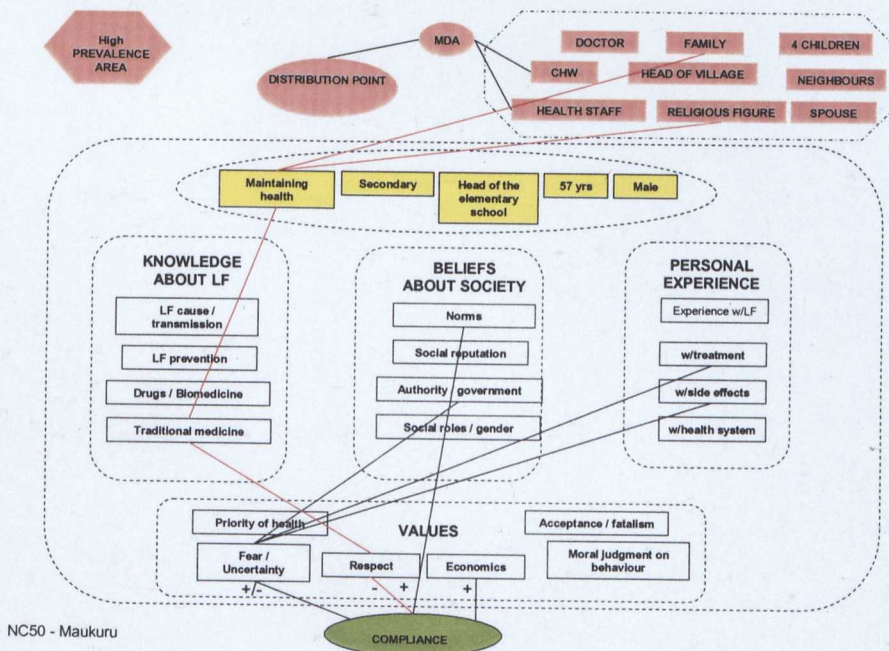






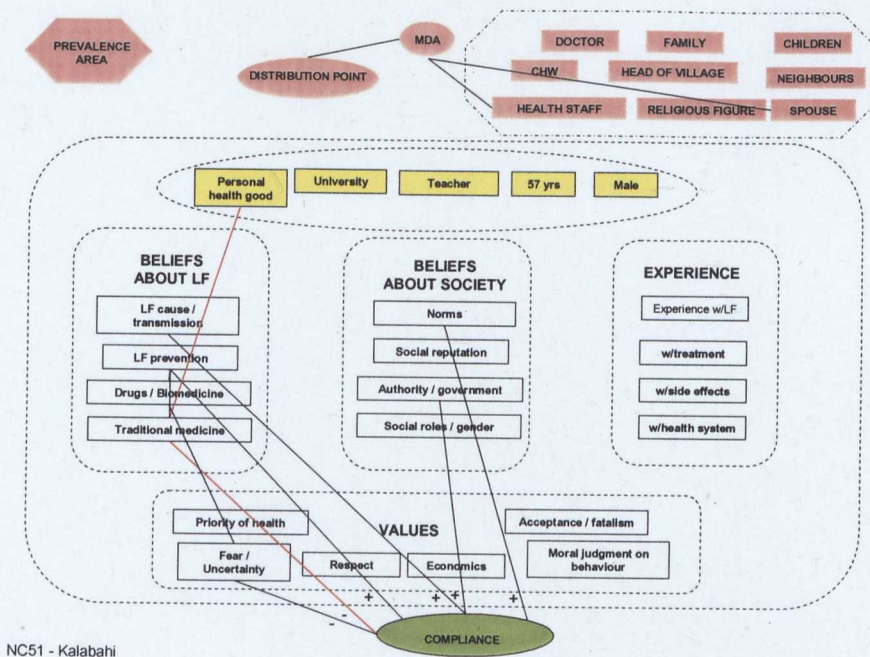


NC48 - Kalabahi

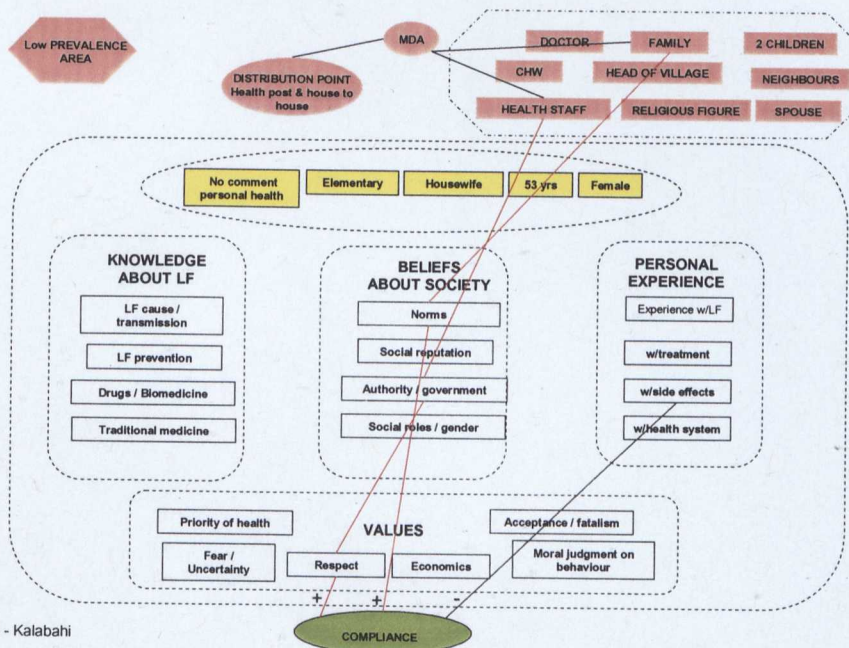


NC50 - Maukuru

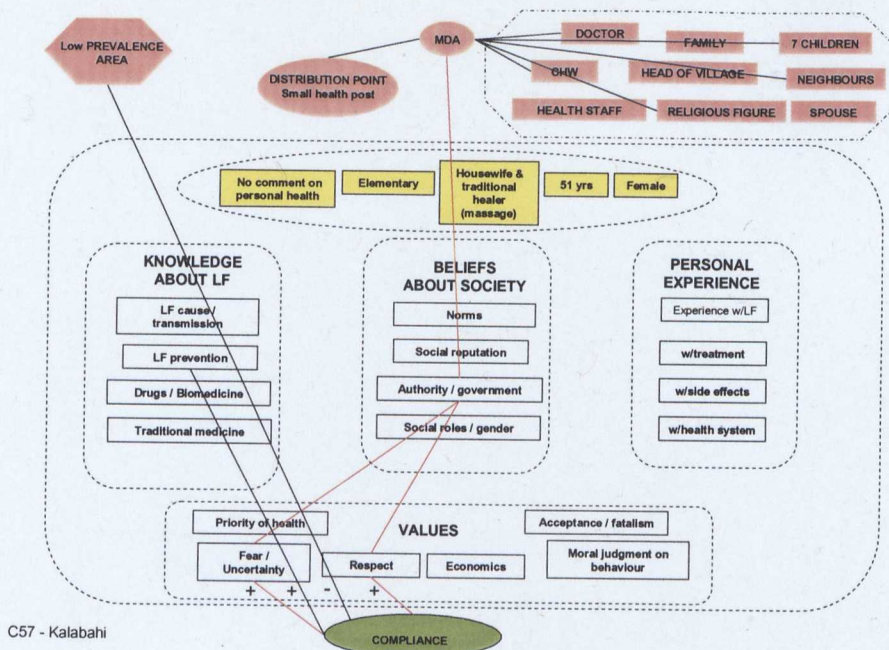




NC51 - Kalabahi



C55 - Kalabahi



C57 - Kalabahi

## **A.11. PARTICIPANT INFORMATION SHEET: INTERVIEWS**

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### **London School of Hygiene & Tropical Medicine (University of London)**

Department of Public Health and Policy  
Public and Environmental Research Unit  
Keppel Street, London, WC1E 7HT  
Phone: 020-7958 8311 Fax: 020-7580 6507



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#### **INFORMATION SHEET**

We are asking for your help to participate in a study about the elimination programme for lymphatic filariasis here in Alor District. It is important that you understand why we are doing this survey, so please read this information sheet carefully. If you have any more questions, ask the interviewer and they will try to answer them for you.

We are interested in why some people take the filariasis medication and why others do not. It does not matter if you did not take the medication or you refused to take the medication in the past, your opinion is still important to us.

We would like to talk to about 30 people in several different villages and in Kalabahi so that we can understand better how this programme is working in different areas. Your participation is entirely voluntary and you are under no obligation to participate. Whether or not you choose to participate, your status and access to health care will not be affected in any way.

If you do choose to help with this study, we will only need about one hour of your time to ask you some questions and to discuss informally. At any time during this discussion, you are free to stop and withdraw from the study. You do not have to give the interviewer a reason.

The information that you provide during our discussion will be completely confidential and we will not even write down your name or address. We will take some written notes during our discussion and if you agree, we may also record the interview using a tape player so that it will be easier to remember what we discussed. All cassettes will remain with the main investigator and your name and address will not be recorded on the cassette or written on it. All tapes will be destroyed after the end of the study.

If you want further information about the study, you can contact:

Alison Krentel  
London School of Hygiene and Tropical Medicine, PHP - PEHRU  
Keppel Street  
London WC1E 7HT, United Kingdom



## A.12. INFORMED CONSENT FORM: INTERVIEWS

### London School of Hygiene & Tropical Medicine (University of London)

Department of Public Health and Policy  
Public and Environmental Research Unit  
Keppel Street, London, WC1E 7HT  
Phone: 020-7958 8311 Fax: 020-7580 6507



#### CONSENT FORM

I have read the information sheet provided or it has been read to me concerning this study and I understand what will be required of me if I participate in this study which will be a verbal interview and discussion.

My questions regarding this study have been answered by:

\_\_\_\_\_.

I understand that at any time I may withdraw from this study without giving a reason and without having any effect on my access to health care.

I agree to take part in this study.

Signed: \_\_\_\_\_  
\_\_\_\_\_

Date:

Witnessed: \_\_\_\_\_  
Date: \_\_\_\_\_

Principal Investigator: \_\_\_\_\_  
Date: \_\_\_\_\_

Alison Krentel  
London School of Hygiene and Tropical Medicine  
PHP - PEHRU  
Keppel Street  
London WC1E 7HT  
United Kingdom